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ABSTRACT

This report to the President and Congress addresses issues affecting people with disabilities from diverse racial and cultural backgrounds, based on a series of meetings which identified remaining barriers to full participation and developed recommendations for improving federal policies and programs. The main barriers which emerged were: (1) "having a seat at the table" (barriers to employment, public accommodations, transportation, and culturally competent service delivery); (2) "getting in the door" (barriers to citizenship); and (3) "being recognized" (barriers to accurate demographic data). The most important recommendation is that an interagency team (composed of representatives from the Departments of Education, Labor, Health and Human Services, Justice, and Housing and Urban Development, along with the Equal Employment Opportunity Commission, Small Business Administration, and Federal Communications Commission) develop and implement a large-scale outreach and training program, targeted to people with disabilities from diverse cultural backgrounds and their families, that will present a series of forums, workshops, and seminars across the country. It is also recommended that interagency teams recruit, train, and contract with people with disabilities to help develop these programs and materials, and that any potential financial barriers to participation be eliminated. The mission statement of the National Council on Disability is appended. (DB)

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# Lift Every Voice

## Modernizing Disability Policies and Programs to Serve a Diverse Nation

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NATIONAL COUNCIL ON DISABILITY
DECEMBER 1, 1999

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National Council on Disability
1331 F Street, NW, Suite 1050
Washington DC 20004-1107

## Lift Every Voice

***Modernizing Disability Policies and Programs to Serve a Diverse Nation***
***Executive Summary***

This executive summary is also available in Spanish, Cantonese, braille, and large print; on diskette and audiocassette; and on the Internet at the National Council on Disability's award-winning Web page (http://www.ncd.gov).

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The views contained in this executive summary do not necessarily represent those of the Administration, because this document has not been subjected to the A-19 Executive Branch review process.

**NATIONAL COUNCIL ON DISABILITY**

*An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.*

## LETTER OF TRANSMITTAL

December 1, 1999

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit NCD's new report on issues affecting people with disabilities from diverse racial and cultural backgrounds, *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation.* We were pleased to release the Executive Summary of this report at the White House Forum on Disability and Cultural Diversity on July 26, 1999, the ninth anniversary of the signing of the Americans with Disabilities Act (ADA).

As you know, there continues to be a large disparity in employment and educational outcomes between people with disabilities and the non-disabled population in the United States. This gap is even more pronounced for people with disabilities who are members of racial or ethnic minority groups. The attached report calls on the Administration and Congress to work to close this gap by making a concerted effort to translate the promise of ADA and other disability laws and programs into real opportunities for children and adults with disabilities from diverse racial and ethnic groups, their families, and their communities. NCD stands ready to work with you and leaders throughout your Administration and Congress to implement the recommendations in this report.

As you have reminded us through your One America initiative, America benefits from the diversity of our citizenry. To fully tap this rich diversity, we must modernize our disability policies and programs so that they are delivered in a culturally competent manner. I look forward to your ongoing leadership to ensure that the American dream is truly accessible to all.

Sincerely,

Marca Bristo

Marca Bristo
Chairperson

(This same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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# LIFT EVERY VOICE AND SING

## "The Black National Anthem"

### James Weldon Johnson, 1900

*Lift ev'ry voice and sing,*
*Till earth and heaven ring.*
*Ring with the harmonies of Liberty;*
*Let our rejoicing rise,*
*High as the list'ning skies,*
*Let it resound loud as the rolling sea.*
*Sing a song full of the faith that the dark past has taught us,*
*Sing a song full of the hope that the present has brought us;*
*Facing the rising sun of our new day begun,*
*Let us march on till victory is won.*

*Stony the road we trod,*
*Bitter the chast'ning rod,*
*Felt in the days when hope unborn had died;*
*Yet with a steady beat,*
*Have not our weary feet,*
*Come to the place for which our fathers sighed?*
*We have come over a way that with tears has been watered,*
*We have come, treading our path through the blood of the slaughtered,*
*Out from the gloomy past,*
*Till now we stand at last*
*Where the white gleam of our bright star is cast.*

*God of our weary years,*
*God of our silent tears,*
*Thou who has brought us thus far on the way;*
*Thou who has by Thy might,*
*Led us into the light,*
*Keep us forever in the path, we pray.*
*Lest our feet stray from the places, our God, where we met Thee,*
*Lest our hearts, drunk with the wine of the world, we forget Thee,*
*Shadowed beneath thy hand,*
*May we forever stand,*
*True to our God,*
*True to our native land.*

James W. Johnson originally wrote this song for a presentation in celebration of the birthday of President Abraham Lincoln. It was adopted as the Black National Anthem in the early 1940s.

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NCD would also like to thank LaDonna Fowler of the American Indian Rehabilitation Rights Organization of Warriors, Mandan Kundu of the Rehabilitation Counseling Program at Southern University and A&M College, and Paul Leung of the Department of Rehabilitation Counseling at the University of North Texas for their assistance.

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# EXECUTIVE SUMMARY

On July 26, 1990, President George Bush signed into law the Americans with Disabilities Act (ADA), one of the most sweeping civil rights laws ever enacted. During the signing ceremony, President Bush emphasized the historic importance of the signing of the Act by comparing it to the fall of the Berlin Wall. "And now I sign legislation which takes a sledgehammer to another wall," he said, "one which has, for too many generations, separated Americans with disabilities from the freedom they could glimpse, but not grasp. Once again, we rejoice as this barrier falls, proclaiming together we will not accept, we will not excuse, we will not tolerate discrimination in America." Then, as he lifted his pen to sign ADA, Bush concluded his remarks by declaring, "Let the shameful wall of exclusion finally come tumbling down."

Nine years later, ADA and the American disability rights movement have produced some tangible results for many Americans with disabilities. In towns and cities across the United States, ADA has produced evolutionary progress in removing barriers that exclude Americans with disabilities and their families. But for a large segment of the population with disabilities, particularly those from diverse racial, cultural, and ethnic communities, a shameful wall of exclusion continues to hinder their ability to participate fully in all aspects of American society. Whether the exclusion stems from one's disability, one's race, one's language, one's culture, one's ethnicity, or a combination of these, the sting of rejection is just as painful. As we mark the ninth anniversary of the signing of ADA, the declaration of equality made in 1990 remains hollow for many people with disabilities from diverse cultural backgrounds in their continuing struggle against the persistent barriers of poverty, inequality, and dual discrimination.

On August 5, 1998, the National Council on Disability (NCD) held a public hearing in San Francisco on "Meeting the Unique Needs of People with Disabilities from Diverse Cultural Backgrounds." This hearing was part of a series of hearings and forums that NCD conducts to develop recommendations for improving the ability of federal policies and programs to serve diverse communities effectively. A roundtable forum in Atlanta and a hearing in New Orleans preceded the San Francisco hearing. To encourage the participation of non-English speakers and specifically to ensure input from the Asian/Pacific Islander and Hispanic communities, the San Francisco hearing was conducted simultaneously in Spanish, English, and Cantonese. Although the hearing participants were from California and Hawaii, the issues raised have application at the national level.

In six hours of testimony at the San Francisco hearing, more than 60 witnesses identified numerous barriers to full participation by minority individuals with disabilities and their families.

Three main barriers emerged from the testimony:

1. Having a Seat at the Table—Barriers to Employment, Public Accommodations, Transportation, and Culturally Competent Service Delivery.
2. Getting in the Door—Barriers to Citizenship.
3. Being Recognized—Barriers to Accurate Demographic Data.

This report follows up on the groundbreaking 1993 NCD report *Meeting the Unique Needs of Minorities with Disabilities*. Many of the findings reported in 1993 remain true six years later. Notwithstanding federal efforts to improve service delivery to minorities and other underserved groups, grassroots consumers have told NCD that little has changed that has resulted in tangible improvements in their day-to-day lives.

This report is not a comprehensive treatment of policy issues affecting minorities with disabilities. Rather, it is intended to spark dialogue about how best to learn from our experiences in the past several years and how to bring the federal disability policy agenda to a new level of inclusiveness and effectiveness, resulting in better outcomes for people with disabilities from diverse cultural backgrounds and their families. The report captures priority issues identified by those who testified in San Francisco, many of whom are native Spanish speakers or native Cantonese speakers. Although the issues raised in San Francisco echoed themes NCD had heard in the public hearings and meetings in Atlanta and New Orleans, some of the issues raised elsewhere were not emphasized at the San Francisco hearing, and some of the priority issues raised in San Francisco received less attention elsewhere.

To broaden the scope of the policy agenda contained in this and other reports that NCD has released in recent years, NCD will host a think tank in spring 2000 to further refine a public policy agenda that is responsive to the needs of all minorities with disabilities, their families, and their communities. Likewise, in winter 2000, NCD plans to issue reports on federal enforcement of the Individuals with Disabilities Education Act (IDEA) and ADA that will include a number of recommendations specifically geared toward making those laws more effective for minorities with disabilities and their families.

NCD looks forward to working with the broader disability and civil rights communities in the coming months and years to elevate the voices it heard in San Francisco, New Orleans, and Atlanta and thereby make the policy landscape more inclusive and responsive to the needs of this important population. The pages that follow include many important recommendations for improving service delivery for minorities with disabilities. However, NCD wishes to highlight one recommendation in particular that has potential to enhance the impact of current policies and programs.

***NCD has learned from grassroots witnesses that the best way to empower minorities with disabilities and their families to take full advantage of federal laws, programs, and services is to provide them with easy-to-understand, culturally appropriate information about what their rights are under various federal laws (e.g., ADA, the Rehabilitation Act, IDEA, the Fair Housing Act) and how best to exercise those rights when a violation occurs.***

***NCD recommends that an interagency team composed of representatives from the departments of Education, Labor, Health and Human Services, Justice, and Housing and Urban Development, along with the Equal Employment Opportunity Commission, Small Business Administration, and Federal Communications Commission, develop and implement a large-scale outreach and training program targeted to people with disabilities from diverse cultural backgrounds and their families that will provide such information directly to the target audiences through a series of forums, workshops, and seminars across the country. These trainings should be repeated on a regular basis so that new people are trained each year and materials routinely updated.***

***This interagency team should work with disability communities, minority communities, other disability, minority, and religious organizations, and other interested organizations to develop a workplan, timetables, and appropriate consultation as it begins its work. In addition, NCD recommends that the interagency team recruit, train, and contract with a core group of people with disabilities from diverse cultural backgrounds and their family members to help develop the written materials and programs that will be used for the trainings, translate them into different languages with awareness of the cultural appropriateness of terminology, and conduct the trainings once the materials are produced. The federal partners should make***

*efforts to include and accommodate often-overlooked groups among the people to be trained and include young adults with disabilities, people with disabilities living on Indian reservations and in other rural or isolated locations, people with mental disabilities, and people with limited English proficiency. Finally, NCD recommends that the federal partners eliminate any potential financial barriers to participation so that the population trained will truly represent the population to be served.*

# I. HAVING A SEAT AT THE TABLE: BARRIERS TO RESOURCES

## A. BARRIERS TO EMPLOYMENT

NCD found in 1993 that "persons from minority backgrounds with disabilities...do not have appropriate training and career development opportunities." NCD believes this finding is still applicable today. On the basis of the low employment numbers for minorities with disabilities and the testimony presented at the 1998 NCD hearing in San Francisco, it is apparent that minority individuals with disabilities still have tremendous difficulty gaining access to culturally appropriate job training and career development opportunities. Although all people with disabilities confront these barriers, the barriers are more persistent and more pronounced for people with disabilities from diverse cultural backgrounds.

While the labor force participation rate for people 18 to 64 years old who do not have disabilities is nearly 83 percent, it is only about 52 percent for those with disabilities, and only about 38.6 percent for non-Whites with disabilities. For people with severe disabilities, the labor force participation rate is about 30 percent for Whites, 21.2 percent for Hispanics, and 17.8 percent for Blacks.

On the basis of the testimony and data reviewed, it seems that in spite of the Rehabilitation Cultural Diversity Initiative begun in 1992, significant racial disparities persist in the delivery of vocational rehabilitation services. In California, these disparities are particularly apparent in the areas of job training and placement services. Moreover, minority individuals with disabilities often have tremendous difficulty obtaining employment with minority-owned businesses because of the stigma attached to disability within many minority communities. In some racial and ethnic communities, as in some White communities, people with disabilities are still perceived as bad for business, as not worth investing in as employees or courting as customers, and in some cases as bearers of bad luck.

NCD's 1993 finding that "persons from minority backgrounds with disabilities...are unable to take full advantage of ADA and other disability policies because of a lack of economic opportunity" is still applicable today. According to witnesses at the San Francisco hearing, few opportunities are available to minority individuals with disabilities for economic independence, particularly entrepreneurial opportunities. In seeking employment, many minority individuals with disabilities encounter significant language and communication barriers, often the direct result of discrimination based on fear and ignorance.

Family members of minority individuals with disabilities have unique needs and confront unique barriers to employment, such as lack of after-school childcare, that have a direct impact on the provision of services for the member with a disability. For the most part, these needs of family members of minority individuals with disabilities have not been incorporated into the larger disability policy agenda, and this failure has had adverse effects on the lives of minority-group members with disabilities.

**Recommendations for Improving Employment Opportunities:**

- *The Department of Labor (DOL), the Small Business Administration (SBA), and the Department of Education should expand funding for culturally appropriate job training and career development opportunities and should require all federally funded programs to demonstrate their ability to meet the language, culture, and disability needs of the whole population in their service areas.*
- *The Rehabilitation Services Administration (RSA) should address the racial disparities apparent in the vocational rehabilitation system, particularly in the areas of job training and placement services.*
- *RSA should strengthen and increase the number of interventions outlined in Section 21 of the Rehabilitation Act, which requires vocational rehabilitation agencies to take action to better address the needs of underserved groups within their service areas.*
- *RSA should conduct compliance reviews of all state departments of rehabilitation to determine the extent to which their efforts to comply with Section 21 of the Rehabilitation Act have produced better outcomes for minorities with disabilities in their state.*
- *The SBA, working with the Presidential Task Force on Employment of Adults with Disabilities, should provide more entrepreneurial opportunities for minority individuals with disabilities to promote economic independence.*

- *Federal, state, and local policy makers should incorporate the unique needs of family members of minority individuals with disabilities into the larger disability policy agenda, particularly in the area of employment.*

One barrier to employment for family members of minority children with disabilities that was mentioned repeatedly at the San Francisco hearing was the lack of accessible, affordable, and integrated childcare and after-school programs. Very few after-school programs are available in California, let alone programs that are affordable, integrated, and accessible. The programs that do meet these criteria tend to have waiting lists of a year or longer. Even where programs do exist, they are rarely staffed with employees trained to work with children of varied abilities and from different cultural backgrounds.

The lack of accessible, affordable, and integrated childcare and after-school programs forces parents of minority children with disabilities to forgo valuable employment opportunities. Parents who cannot afford to stay home with their children testified about turning to extreme measures, including locking their disabled children in their rooms—a practice that was noted by a substantial number of witnesses at the 1998 hearing. Put simply, the childcare shortage in California and other states has reached crisis proportions for low-income parents of children with disabilities, many of whom are minorities.

Recommendations for Improving Access to Childcare:

- *The Department of Justice (DOJ) should place a high priority on investigations to assess compliance with ADA Title III mandates for access among social service center establishments serving children.*
- *The Departments of Education and Justice should place a high priority on investigations of school district compliance with IDEA least restrictive environment requirements in the implementation of district-provided after-school programs.*
- *Congress should appropriate funding to increase the supply of accessible, affordable, and integrated childcare and after-school programs and should require that all federally funded programs not only meet federal disability access standards but also demonstrate*

*the capacity to meet the language, cultural, and disability needs of their entire service population.*

- *The Departments of Education, Justice, and Health and Human Services (HHS), including the federally funded legal services programs and protection and advocacy systems, should increase outreach efforts to parents of minority children with disabilities regarding their rights under ADA, IDEA, section 504 of the Rehabilitation Act, the Fair Housing Act, and other federal disability civil rights laws.*

## B. BARRIERS TO PUBLIC ACCOMMODATIONS

NCD's 1993 finding that "persons from minority backgrounds with disabilities...have greater difficulty...gaining access to public accommodations...than do other Americans with disabilities" is still applicable today. More than 20 percent of the witnesses who testified at the San Francisco hearing said they confronted multiple barriers when trying to gain access to public accommodations such as restaurants, markets, and other local establishments, and that this often occurred in their own cultural communities (such as Chinatown in San Francisco). Minority individuals with disabilities and their family members who testified attributed the continued lack of access to public accommodations to the lack of compliance with existing access mandates in Title III of ADA and to the lack of awareness of those requirements among protected individuals and covered entities in minority communities.

Serious gaps exist in the legal protections afforded minority individuals with disabilities and their families, particularly in the area of access to public accommodations. Unlike IDEA, which has specific language supporting the rights of ethnic minority families whose primary language is not English, ADA and most other disability laws and policies fail to address the unique language and communication needs of minority individuals with disabilities and their families for whom English is a second language. Moreover, many American Indian tribes have no civil rights law for tribe members with disabilities.

Recommendations for Improving Access to Public Accommodations:

- *Congress should require federal enforcement agencies such as DOJ, the Equal Employment Opportunity Commission (EEOC), the Department of Transportation (DOT), and the Department of Housing and Urban Development (HUD) to demonstrate their effectiveness in serving people with disabilities from diverse cultural backgrounds.*
- *Federal enforcement agencies should work together to develop a multiagency outreach and technical assistance strategy that would constitute a national campaign to increase knowledge of civil rights protections and how to file complaints among protected communities, focused on underserved groups such as language, racial, and ethnic minorities, youth, and rural residents with disabilities and their families.*
- *Congress should ensure that civil rights enforcement agencies have adequate financial and staffing resources to address the needs of their entire service areas effectively.*
- *Congress and the Bureau of Indian Affairs should provide federal financial support and assistance for the development of tribal disability rights legislation.*

## C. BARRIERS TO TRANSPORTATION

NCD's 1993 finding that "persons from minority backgrounds with disabilities...have greater difficulty...gaining access to...transportation than do other Americans with disabilities" is still applicable today. Nearly one in five witnesses who testified at the hearing in San Francisco said they encountered multiple barriers.

One issue brought up repeatedly at the hearing was the perceived unwillingness on the part of public transportation personnel to accommodate minority individuals with disabilities and implement existing requirements for access to public transportation. Several parents who testified at the hearing said this problem is especially acute for minority children with disabilities. According to these parents, public transportation personnel have been unwilling to assist minority children with disabilities in getting on and off the bus and in finding the appropriate stop. Minority individuals with disabilities who speak English as a second language or who do not speak English at all face additional language and communication barriers when attempting to use public transportation. Some respondents testified that public transportation personnel are less helpful to these minority individuals who speak limited or no English.

The number of transportation options available to minority individuals with disabilities who live in isolated areas and rural communities is limited, especially in the Pacific Islands. Although most Americans with disabilities occasionally have to wait a long time for public transportation, witnesses at the San Francisco hearing asserted that because of their disability and racial identity, drivers were even less likely to pick them up. Witnesses said they had sometimes been forced to wait four to six hours before public transportation personnel would finally stop and pick them up, and as a result of this discrimination they missed important medical or other appointments.

Recommendations for Improving Access to Transportation:

- *DOT and/or DOJ should investigate the extent to which local compliance with ADA transportation requirements is influenced by race and ethnicity.*
- *Congress should ensure that transportation civil rights enforcement agencies have adequate financial and staffing resources to maintain an adequate presence with covered transportation entities to ensure compliance.*
- *DOT should make funds available for local transportation providers to offer ongoing diversity and disability awareness training for all public transportation personnel, as well as specific training on the public transportation provisions of ADA.*
- *DOT should create incentives for local transportation providers to increase efforts to hire bilingual public transportation personnel in service areas with high concentrations of non-English speakers.*

## D. BARRIERS TO CULTURALLY COMPETENT SERVICE DELIVERY

### 1. Minority Representation in Disability Service Professions

NCD's 1993 finding that one of the main barriers to culturally competent service delivery for minority individuals with disabilities is the lack of minority representation in disability service professions is still applicable today. Half of the participants at the San Francisco hearing testified about the difficulty they have in getting culturally competent services because of the lack of minority individuals in disability service professions.

One area where the lack of minority representation is particularly apparent is disability-related counseling services. Several respondents at the hearing stressed the tremendous need for cultural identification between clients and counselors in the provision of culturally appropriate counseling services. In a recent national study funded by the National Institute on Disability and Rehabilitation Research (NIDRR), 82 state rehabilitation agencies (general and blind) were surveyed about the racial and ethnic composition of their workforces. Within the 56 agencies responding, the aggregate breakdowns of their staffs were 87.4 percent Caucasian American, 7.7 percent African American, 1.9 percent Hispanic American, 2.9 percent Asian American and Pacific Islander, and 0.1 percent other. Within district offices, which tended to have lower salaries across the board, the staffs were reported as 79.5 percent Caucasian American, 13.3 percent African American, 4.8 percent Hispanic American, 1.7 percent Asian American and Pacific Islander, and 0.5 percent Native American. The same study found that professionals of minority backgrounds are significantly underrepresented nationally.

Another area that has lacked minority service personnel is special education. Witnesses at the hearing testified that few bilingual/bicultural school personnel are found in special education. According to statewide special education data, more than half (57%) of the students enrolled in special education in California are from minority communities, while fewer than 15 percent (14.9%) of the special education teachers in the state are minority and almost 85 percent (84.3%) are White.

Hearing participants believe that this racial imbalance leads to conflicting expectations and poor parent-teacher communication, particularly in rural areas. Witnesses at the hearing also testified that there are few, if any, special education mediators and hearing officers of color.

particularly African Americans. In the California special education hearing offices, there are no special education mediators of color, and only three of the eight hearing officers are from minority communities. Furthermore, no special education mediators or hearing officers in California are African American. Because minority contract preferences have been deemed unconstitutional as a result of Proposition 209, the hearing office cited above has made no effort to conduct targeted recruitment and hiring of minority individuals and women.

Hearing participants pointed out the lack of disability service personnel who are not only members of racial and ethnic minority groups, but also people with disabilities. Just because people are bilingual or bicultural does not mean they will understand and be sensitive to the needs of people with disabilities from minority communities, particularly given the stigmas attached to disability within these communities. Several witnesses who were recent immigrants noted that this issue is further complicated by generational differences and immigration status.

Another difficulty that affects culturally competent service delivery is the absence of minority individuals with disabilities in positions of decision-making power. According to witnesses at the hearing, this problem is particularly apparent in the composition of the general and administrative staff for California's network of independent living centers. According to the Section 704 Report for 1997, more than 50 percent of the general staff for the state's independent living centers are members of minority communities, and at least 60 percent are people with disabilities. More than 60 percent of the decision-making staff, however, are White.

Of the 18 current state independent living council (SILC) members in California, furthermore, only 1 is a person from a minority community. Section 705(b)(4) of the Rehabilitation Act of 1973 requires that a majority of all SILC members be persons with disabilities, but there is no similar requirement to ensure appropriate minority representation.

Recommendations for Improving Diversity of Disability Service Providers:

- *The Departments of Education, HHS, and Labor should increase incentives for minority individuals, particularly minority individuals with disabilities, to enter disability service professions and to be afforded educational and professional development opportunities after entry. For example, the Department of Education should enhance funding for scholarships funded through the Office of Special Education and Rehabilitative Services* *to minority institutions of higher education to increase the number of qualified graduates of culturally diverse backgrounds, especially those with disabilities.*

- *RSA and the Office of Special Education Programs (OSEP) should continue their efforts to increase the number of minority professionals working in vocational rehabilitation, special education, independent living, and related services, and other disability service agencies should create similar initiatives. For example, Rehabilitation Capacity Building initiatives should be used to develop new programs in Historically Black Colleges and Universities, Hispanic Serving Institutions, Native American Serving Institutions, and Asian American/Pacific Islander Serving Institutions, which will increase the number of qualified rehabilitation personnel of diverse cultures in the system.*
- *RSA and other federal funders should require disability service providers to have a demonstrated commitment to workplace diversity and family-friendly policies. Along these lines, RSA should mandate hiring of a higher percentage of graduates (RSA scholarship recipients) of the programs mentioned above each year to fulfill the Comprehensive System of Personnel Development needs of every agency.*
- *Congress should appropriate adequate funding to the EEOC, DOJ, HUD, DOT, and the Department of Education to enable them to conduct disability rights training for minorities with disabilities, their family members, and bilingual individuals, with the goal of creating a core group of culturally diverse individuals in every state who can train additional individuals in the requirements of federal civil rights laws and how to use those laws when a violation occurs.*
- *The Department of Education should issue a policy memorandum mandating targeted recruitment and hiring of bilingual and bicultural special education staff at all levels.*
- *OSEP, along with the Office for Civil Rights at the Department of Education, should investigate the racial and ethnic composition of special education mediators and hearing officers nationally and the extent to which race and ethnicity influence mediation and due process outcomes.*

- *Federal funding agencies such as the Departments of Education, HHS, and Labor should encourage voluntary public disclosure of diversity data for entities receiving federal funds. In addition, federal agencies such as RSA should require an annual cultural competency assessment for every state agency and maintain a national database containing the following personnel information: position, ethnicity, gender, disability status, education, certification/licensure, and salary.*
- *NIDRR should fund a longitudinal study on participation of culturally diverse professionals in the rehabilitation system. In addition, NIDRR should fund research on such factors as rehabilitation outcomes and educational outcomes as a function of counselor/teacher ethnicity, gender, disability, education, and professional competency.*

### 2. Culturally Appropriate Outreach

NCD's 1993 finding that minority individuals with disabilities and their families are largely unaware of the services and resources available to them because "there have been insufficient outreach efforts" to these individuals by federal, state, and local agencies is still applicable today. More than 4 in 10 of the participants at the San Francisco hearing indicated that minority individuals with disabilities and their families are still unaware of the services and resources available because of the inadequacy of culturally appropriate outreach efforts to these populations.

Participants in the hearing noted that there is a tremendous lack of awareness among minority populations about the existence of ADA, and about the specific rights that are guaranteed under the Act. One group that has particular difficulty gaining access to necessary information and resources is parents of minority children with disabilities who have limited English or speak no English. Several witnesses at the hearing said that lack of access to information and resources substantially limits the ability of parents of minority children with disabilities to exercise their rights and responsibilities under the law and to obtain necessary services for their children.

A large number of hearing participants testified that the lack of awareness among minority individuals with disabilities and their families indicates a failure of federal, state, and local agencies to provide information in a way that is culturally and linguistically appropriate and that considers the fundamental differences between majority and minority cultures.

Many U.S. minority groups hold collectivistic value orientations that emphasize the importance of family and interdependence. This orientation is often in direct contrast with the U.S. majority culture, which is highly individualistic and places a high value on personal autonomy and independence. Because of these cultural differences, concepts such as "individual empowerment," "self-sufficiency," "independent living," "control over one's life," and "minimal reliance on others" may be isolating and even offensive to a minority individual with a disability if they are not adequately translated and presented in a culturally appropriate manner.

There are significant cultural differences in the perception and impact of disability on the individual and the family. Many U.S. minority cultures view disability as a reflection upon and responsibility of the entire family. U.S. majority culture, on the other hand, tends to view disability primarily as an individual matter. According to witnesses, the sense of family responsibility for disability within many minority cultures stems from the negative perception of disability within those cultures. A large number of minority group members typically view disability as a shameful or negative reflection upon the whole family.

There is a tremendous need for education and outreach to minority individuals with disabilities, their families, and their communities in order to provide support to them in dealing with the impact of disability and, in turn, to increase their awareness about available resources and ways to integrate the experience of disability into one's life, one's family, and one's community without shame or unnecessary sacrifice of one's goals.

There is an equally profound need to increase awareness about minority cultural issues within the mainstream disability community. According to witnesses at the hearing, most disability organizations know very little about linguistic and cultural access for minority individuals with disabilities. Linguistically and culturally appropriate outreach is often hampered by the failure of federal agencies to renew grant funding specifically earmarked for this purpose. Culturally appropriate outreach requires a long-term commitment and a continued presence in minority communities in order to establish the sense of trust that is necessary for outreach efforts to be successful. When funding is not renewed, outreach efforts are substantially and negatively affected.

Recommendations for Improving Culturally Appropriate Outreach:

- *Congress should amend the definition of "Minority Entities" under Section 21 of the Rehabilitation Act to once again include "Community-Based Minority Organizations," which were deleted from the definition in the 1998 amendments.*
- *Congress should ask the General Accounting Office (GAO) to investigate the cultural and linguistic appropriateness of public information activities related to ADA, IDEA, the Fair Housing Act, and other federal disability civil rights laws.*
- *The Departments of Education, HHS, HUD, Transportation, and Labor, as well as the SBA, should require their grantees and field offices to develop a culturally appropriate outreach plan that takes into account the fundamental differences between majority and minority cultures.*
- *NIDRR should require its research and training centers with emphasis on minority populations to develop and test guides describing the services provided by independent living centers that use appropriate cultural and linguistic terminology for diverse populations. Once these guides are produced, RSA should require centers for independent living (CILs) and SILCs to use these guides to improve their outreach and service delivery to diverse populations.*
- *Federal agencies funding outreach efforts should encourage initiatives directed not only toward minority individuals with disabilities, but also toward their families and racial and ethnic community organizations.*
- *Federal agencies conducting or funding outreach should emphasize that successful outreach requires an awareness of the perception of disability and related issues, such as independent living, that exists within a particular cultural community.*

### 3. Language and Communication Barriers

NCD's 1993 finding that one of the main barriers to culturally competent service delivery for minority individuals with disabilities is the failure to address their "language and communication" needs is still applicable today. Approximately 4 in 10 of the participants at the San Francisco hearing testified about their difficulty in gaining access to culturally competent services because of language and communication barriers.

For minority individuals with disabilities who speak limited or no English, language barriers are a major obstacle to obtaining necessary resources because there are so few bilingual service providers, interpreters, and language-appropriate materials. The lack of language capacity among many disability service providers was noted at the hearing as significantly limiting access to information about rights, benefits, employment programs, and other support services and opportunities.

The need for bilingual service providers is particularly critical in special education. According to witnesses at the hearing, parents of children with disabilities who speak limited or no English face significant language barriers when they attempt to enroll their children in special education, obtain related services, and participate in everyday, informal communication with school personnel. Among the difficulties they mentioned were evaluating interpreter skills, finding and paying for an interpreter with the particular language needed, and having interpreters available when needed.

Cheryl Wu and Nancy Grant, of the Hearing Society for the Bay Area, noted that interpreting or translation often addresses only words and does not take into account the need for translation of cultural concepts, behaviors and body language, expectations about relationships, and jargon (medical terms or educational and legal acronyms). When dealing with service providers, minority individuals with disabilities encounter significant communication problems because of cultural differences in body language and communication styles.

Other language and communication barriers mentioned at the hearing include a lack of direct telephone access when answering systems use English as the only language option, limited funding for translation and interpretation services, and the absence of translated materials in alternative formats such as braille, audiocassettes, and large print.

A follow-up study conducted after the hearing by Kathy Abrahamson and Kathy Knox, of the Rose Resnick Lighthouse for the Blind in San Francisco, concluded that an additional language and communication barrier for people from diverse cultural communities who are blind or visually impaired is the absence of language-appropriate materials available in alternative formats, particularly from government agencies.

Recommendations for Removing Language and Communication Barriers:

- *The departments of Education, HHS, HUD, Transportation, and Labor, as well as the SBA, should require that their field offices and grantees conduct targeted recruitment and hiring of minority individuals who are bilingual and bicultural, especially minority individuals with disabilities.*
- *The Office of Special Education and Rehabilitative Services should issue a policy memorandum mandating targeted recruitment and hiring of bilingual special education staff at all levels.*
- *RSA should include language interpreter information and referral as a core service at all centers for independent living that have significant populations of non-English-speaking people within their service areas.*
- *RSA should require all CILs with significant non-English-speaking populations in their service area to develop language and communication action plans that include the following:*
    - *Establishing contacts within minority community agencies who can assist in facilitating communication with ethnically diverse populations.*
    - *Developing a language interpreter referral database that is available in multiple languages and alternative formats, including the World Wide Web.*
    - *Sending all existing or new translated materials to the SCLC for widespread distribution to other centers for independent living and related agencies and organizations in the state.*

  - *Establishing sign language and other language interpreter and translator training programs that provide instruction on translation of cultural concepts, behaviors and body language, expectations about relationships, and other technical disability-related terms (medical terms, educational and legal acronyms).*
  - *Providing language-dedicated telephone lines in Spanish and other languages, and information in bilingual formats on Web pages.*

- *The departments of Education, HHS, HUD, Labor, and Transportation, as well as the SBA should make available adequate funding to all field offices and grantees for translation and interpretation services.*

- *Congress should ask GAO to investigate the quality of service delivery for minority individuals with disabilities and their families in terms of language and cultural competence.*

## II. GETTING IN THE DOOR: BARRIERS TO CITIZENSHIP

The United States has a long and well-documented history of actively discouraging and restricting the immigration and citizenship of people with disabilities, especially those from certain racial and ethnic communities. This historical pattern continues today through the subtle yet equally exclusionary practice of denying immigrants with disabilities their right to reasonable accommodations in the naturalization process.

Following passage of the 1996 welfare reform law, many immigrants with disabilities throughout the United States faced the possibility of losing necessary Social Security and food stamp benefits if they did not become U.S. citizens. In California, almost 74 percent of the legal noncitizens in the state stood to lose not only Supplemental Security Income (SSI) and food stamp benefits, but also Medicaid and In-Home Supportive Services (the state name for home-based personal assistance services) as a result of categorical eligibility requirements if they had failed to naturalize and attain U.S. citizenship before the enactment of federal welfare reform.

At the time of the San Francisco hearing in 1998, citizenship continued to be withheld from many qualifying immigrants with disabilities because the Immigration and Naturalization Service (INS) denied them reasonable accommodations and policy modifications during three stages of the naturalization process: the naturalization interview, fingerprinting, and the execution of a "meaningful" oath of allegiance.

Only in the past year or so has the INS begun to take its obligations under the Rehabilitation Act seriously. It has formed a national working group with community-based organizations that is helping to develop needed field guidance and policy modifications for naturalization processing and adjudication. On April 7, 1999, INS issued comprehensive new guidance to its field adjudicators that is intended to simplify and streamline the review of form N-648, which excepts persons with certain disabilities from the English language and U.S. civics knowledge requirement for naturalization. INS also is revising form N-400, the naturalization application, and is planning to include a new section on the revised form that will allow applicants to indicate that they will need a reasonable accommodation during their interview (e.g., sign language interpreter, home visit). In addition, INS announced a new fingerprint waiver procedure, effective in summer 1999, waiving the fingerprint requirement for applicants who cannot produce classifiable fingerprints because of a disability and instead requiring that they be instructed to obtain a local police clearance memorandum.

The April 7, 1999, memorandum also included guidance to field adjudicators on determining whether certain applicants with severe disabilities understand the oath of allegiance. The guidance instructed adjudicators to communicate with the applicant through a family member, if the family member can aid in communicating with the applicant; to use "yes or no" questions that the applicant might more readily be able to answer; and to accept whatever form of communication the applicant uses, including blinks and nods.

**Recommendations for Improving the Naturalization Process:**

- *Congress should ask GAO to conduct a study of INS compliance with disability access mandates under federal law, examining in part whether the changes put in place in the past year have resolved the long-standing problems identified in this report.*
- *INS should conduct training for field staff regarding the new procedures and policies outlined in its April 7, 1999, memorandum. Such training should be completed by October 1, 1999.*
- *Congress should amend the Immigration and Nationality Act to provide for a disability waiver for the oath of allegiance requirement.*
- *INS should ensure timely processing of naturalization applications for applicants with disabilities.*
- *The Disability Rights Sections of the Civil Rights Divisions of DOJ, NCD, and INS should work together to monitor implementation of INS's recent efforts to address long-standing problems with its naturalization process regarding access for applicants with disabilities, and to address ongoing problems as they occur. To further this effort, DOJ should institute a toll-free number to a central location staffed with trained multilingual employees so that anyone having problems with accommodations in the naturalization process could raise those issues and have the staff take steps to address both the*

*individual and the systemic issues identified. This toll-free number should be publicized in numerous languages in every INS office and on INS forms and materials.*

# III. BEING RECOGNIZED: THE NEED FOR ACCURATE DEMOGRAPHIC DATA

Over the past 30 years, the United States has seen significant changes in the racial and ethnic makeup of its population. Many of these changes were felt first and most powerfully in California, a harbinger of what other large states will encounter. With the turn of the century, California becomes the first continental state in America with a majority population of racial and ethnic minorities. This shift has substantial political, economic, and social ramifications.

The federally funded disability service provider network in California will need to revisit assumptions about the prevalence of disability among Hispanic and Asian/Pacific Islander populations and subpopulations and the emphasis placed on service delivery for individuals with disabilities in those communities. This need will expand beyond California as other states undergo similar population shifts. The importance of accurate demographic data is underscored by the reliance on such data, particularly census data, by state and county agencies in planning for eligible recipients under Medicare, Medicaid, and SSI programs; by rehabilitation agencies in distributing funds and developing programs under the Rehabilitation Act; by HUD in distributing funds for housing for people with disabilities; and so on. In short, all levels of government use census information to guide the annual distribution of $180 billion in critical services to people with disabilities and their families.

According to the national estimates, the rate of disability in Hispanic and Asian/Pacific Islander populations is significantly lower than for other racial or ethnic groups, including Whites. Some researchers, however, believe that these estimates do not accurately reflect the prevalence of disability in Hispanic and Asian/Pacific Islander populations and subpopulations because of a variety of socioeconomic factors and acculturation variables, including immigration status and the perception of disability within these cultures. These variables have an impact on the self-reported rate of disability in Hispanic and Asian/Pacific Islander populations and subpopulations.

Service delivery systems have been developed and focused on the needs of the majority with some added attention to African Americans and Native Americans with disabilities. Partly for lack of data, the needs of Hispanics and Asians/Pacific Islanders with disabilities have been largely ignored.

Recommendations for Improving the Accuracy of Demographic Data:

- *The Census Bureau and the Bureau of Labor Statistics, working with NIDRR and the National Center for Health Statistics, should develop alternative methods for tracking the prevalence of disability within racial/ethnic minority communities at the national, state, and local levels.*
- *The Census Bureau should make affirmative efforts to hire minority and bilingual individuals with disabilities as part of the workforce that will assist with Census 2000.*
- *NIDRR and other federal research entities should conduct studies that explore the intra-ethnic experience and prevalence of disability.*

NCD believes that every person with a disability, regardless of race or ethnicity, should have the opportunity to realize the promise of freedom and equality made in ADA. The importance of racial and ethnic diversity must be recognized as a key component of the disability civil rights movement in the new millennium. These recommendations are submitted in the belief that they will promote that recognition and begin the process of tearing down the shameful wall of exclusion that has prevented minority racial and ethnic individuals with disabilities and their families from participating fully in all aspects of American society.

## A. INTRODUCTION

On July 26, 1990, President George Bush signed into law one of the most sweeping civil rights laws ever created, the Americans with Disabilities Act. During the signing ceremony, President Bush emphasized the historic importance of the signing of the Act by comparing it to the recent fall of the Berlin Wall. "And now I sign legislation which takes a sledgehammer to another wall," he said, "one which has, for too many generations, separated Americans with disabilities from the freedom they could glimpse, but not grasp. Once again, we rejoice as this barrier falls, proclaiming together we will not accept, we will not excuse, we will not tolerate discrimination in America."[1] Then, as he lifted his pen to sign ADA, Bush exhorted, "Let the shameful wall of exclusion finally come tumbling down."

Nine years later, as the 10th anniversary of the signing of ADA approaches, this majestic declaration of inclusion and equality rings true for many Americans with disabilities. For a large segment of the population, however, and particularly for those from diverse cultural and ethnic communities, the shameful wall of exclusion is still a reality. The declaration of equality made in 1990 remains hollow for these individuals as they continue to struggle against the persistent barriers of poverty, inequality, and discrimination.

On October 21, 1992, the National Council on Disability held a public hearing in San Francisco to determine how minority group members with disabilities were faring under ADA. The testimony reflected what is now a well-documented fact: that people with disabilities from diverse cultural communities not only experience poverty and disability at a disproportionately higher rate, they also face language, cultural, and attitudinal barriers that significantly impede their access to resources and accommodations. Based on these and other findings, NCD in 1993 produced its report, ***Meeting the Unique Needs of Minorities with Disabilities***. In it, NCD articulated an agenda that identified the unmet needs of minority individuals with disabilities as a national policy priority[2] and set a vision for inclusion and equality for minority group members with disabilities in society.

About six years after the original hearings, on August 5, 1998, NCD held a second hearing in San Francisco to examine how well ADA and other public policies related to minority communities. NCD found that in spite of the progress made in disability policy in the decade of the 1990s, minorities with disabilities are still plagued by the poverty, inequality, and discrimination that they testified about years before.

At the 1998 NCD hearing in San Francisco, 69 advocates, people with disabilities, and their families, from diverse cultural communities in California and Hawaii and other Pacific islands, came forward to ask that NCD revisit the agenda it had articulated in 1992 and work to realize immediate change so that the promises of ADA and other disability laws would be felt in these diverse communities. In effect, they wanted to cash in a check that had been given to them that historic day in 1990 on the South Lawn of the White House. When the architects of ADA wrote that "the nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency,"[3] they signed a promissory note for all Americans with disabilities, regardless of the color of their skin.

Based on the testimony of witnesses at the 1998 hearing, it seems that America has defaulted on this promissory note to minority citizens with disabilities. The similarities between the policy problems that emerged in the 1992 and 1998 testimonies are a grim reminder that the wall of exclusion still exists, and that it continues to separate minority individuals with disabilities from the freedom they only glimpse, but do not yet grasp.

At the 1998 hearing in San Francisco, people with disabilities from diverse cultural backgrounds issued a challenge to each other, as well as to their governmental representatives and respective cultural communities—a challenge to take immediate action, to "tear down this shameful wall" of exclusion once and for all, and to demonstrate a commitment to profound change. In succinct and pointed testimony, Leroy Moore, Jr., co-founder of the Disability Advocates of Minorities Organization in the Bay Area, took the lead in issuing this call to action:

> It's up to us, not our leaders, not our ethnic or disabled organizations, but us, to come together, organize, let our voices be heard, and talk about racism and disabledism within our organizations that are supposed to serve and advocate on behalf of us....This is our issue and our time to be advocates, be delegates and teachers of our communities and organizations. I was here at the same conference in 1992, and I have to say very little has changed because we the public are not taking this issue into our own hands....Please don't let another [six] years go by before we get back together again.

David Freeman, of the San Francisco State University Institute on Disability, echoed this sentiment:

> Everything we have done up until this point is not enough. Simple platitudes will no longer placate us. Broad and bold steps need to be taken. We have to go further than we have ever gone before.

Underlying these two statements is a fierce sense of urgency and a denunciation of the policy of gradualism that has characterized efforts to address the unique needs of people with disabilities from diverse cultural populations up until now. The lessons from the 1990s make clear that the "shameful wall of exclusion" will not come "tumbling down" through enactment of laws. Concrete steps are needed to ensure that the unique needs of minority individuals with disabilities and their families are adequately met. Institutional requirements of compliance and accountability must be established that will have the full force of the law behind them. Minority individuals with disabilities themselves also need to heed the "call to action" and spearhead the effort to generate change within their cultural communities, thereby collectively altering their social status within those communities.

The ideas and proposals that NCD discusses in the following pages are significant because they were developed in the spirit of this "call to action" through the assistance of a Report Team made up of three women and three men who have a variety of disabilities and the majority of whom are members of different ethnic minority groups (including an Asian American, a Latina, a Native American, and an African American).

Many of the issues at the San Francisco hearing were consistent with issues that NCD has identified as important for all people with disabilities, regardless of racial or ethnic identity. For example, a large number of people testified about the dehumanizing and degrading experience of going to a local Social Security Administration (SSA) office to apply for benefits. Much of this unfortunate experience was related to disability, and much was directly related to race and ethnicity. Many individuals with disabilities, for example, complain of a typical pattern of disrespect at SSA offices, regardless of their racial or cultural background. In addition to this disrespect, individuals with disabilities from diverse cultural communities often face other challenges from SSA personnel, including a lack of cultural competence or understanding, communication differences, and failure to deal with cultural specifics and language needs. Although all individuals with disabilities who are members of racial and ethnic minority groups encounter the same challenges as other individuals with disabilities, persons with disabilities from ethnic populations face unique problems because of socioeconomic, cultural, and other factors which must be addressed if they are to benefit equally from public policies and programs.[4]

The primary goal of this report, therefore, is not to identify the general issues and problems that exist for all people with disabilities, but rather to focus specifically on the barriers encountered by individuals with disabilities from diverse cultural communities because of their racial and ethnic status. NCD identified within the testimony three primary barriers to equality for people with disabilities from minority communities. These barriers are a lack of resources, culturally inadequate service delivery, and inadequate and misleading demographic data.

The following pages propose specific steps to address these barriers. This report outlines an agenda that requires immediate attention. If implemented, this agenda will be a sledgehammer on the "shameful wall of exclusion" that continues to exclude minorities with disabilities from full participation in American society.

## B. BARRIERS TO RESOURCES

### 1. Overview

This chapter discusses barriers that minorities with disabilities confront in getting access to resources they need to become independent, economically self-sufficient, and an integral part of their communities. The disadvantages of ethnic and disability status have a combined effect that is often greater than the sum of the parts. Federal disability rights and services tend to be monitored less closely in minority communities. Small gaps in communication can result in major disparities in the understanding of laws.

NCD recommends that the U.S. Department of Education strengthen efforts to include minorities with disabilities as equal beneficiaries of all education, rehabilitation, and independent living programs. NCD recommends that the U.S. Departments of Interior and Justice work together to promote rights and services for Native Americans with disabilities within Indian communities. NCD recommends that the U.S. Department of Transportation provide more technical assistance and public education to improve transit accessibility in diverse cultural communities.

### 2. Analysis

In his testimony at the 1998 NCD hearing in San Francisco, H. Leon Cain, of Resources for Independent Living in Sacramento, requested that the "National Council on Disability identify any progress that has been made" since the "previous hearing" in 1992. The testimonies presented at the 1992 and 1998 NCD hearings in San Francisco reveal a disturbing similarity in the issues raised. As Leroy Moore, Jr., said in his testimony, "I was here at the same conference in 1992, and I have to say very little has changed." Rather than being a decade of progress, the 1990s has, in some ways, been a decade of decline for people with disabilities from diverse cultural backgrounds.

Evidence of this decline can be found throughout the service delivery system, but it is most apparent in the area of access to resources. Minority individuals with disabilities experience tremendous "difficulty in gaining access to the resources needed to become self-sufficient" and it remains essentially as true today as it was six years ago. Almost 50 percent of the people who testified at the 1998 NCD hearing identified the lack of access to resources as the main problem facing minority individuals with disabilities today. Although the concepts of "access" and "accessibility" are routinely associated with issues of physical and architectural access, when considered in the context of the unique needs of people with disabilities from minority communities, these words take on a different meaning. "Access" for some minority individuals with disabilities involves not only issues of overall physical access (such as architectural, technological, geographical, and environmental accessibility), but also culturally defined issues of access, such as access to information, language and communication needs, and culturally competent service delivery. Because of these additional barriers and accessibility issues, minority individuals with disabilities face an even greater challenge than other people with disabilities in gaining access to necessary resources. Judging from testimony presented in 1998, that challenge has arguably increased in scope and intensity over the course of the past six years.

Almost 40 percent of the people who testified in 1998 expressed difficulty in gaining access to employment; more than 20 percent had difficulty getting into public accommodations, and another 20 percent had difficulty using public transportation. Examples drawn from the testimony illustrate the extent of the difficulties that minority individuals with disabilities currently face in getting necessary resources in the areas of employment, public accommodations, and transportation.

### a) Employment

According to the report of the 1992 hearing, one major finding was that "persons from minority backgrounds with disabilities...do not have appropriate training and career development opportunities," and they "are unable to take full advantage of ADA and other disability policies because of a lack of...economic opportunity." In order to address this situation, NCD recommended in its 1993 report that "appropriate funds" be given to "public agencies and private community-based entities to develop and implement training and to provide opportunities for economic independence for minorities with disabilities."[5]

One organization that acted upon this recommendation was the Association for Retarded Citizens (ARC) in San Francisco. In 1994, ARC San Francisco received a grant from the U.S. Department of Education to administer a three-year demonstration project called the "Multicultural Employment Program." According to the 1998 testimony of Shiva Shultz, director of the program, the main focus was to "assist immigrants with disabilities from Chinese, Filipino, Russian, and Hispanic communities in becoming employed in integrated work sites in the community." By taking the approach of "focusing on the positive aspects of these immigrant cultures" and "matching the cultural needs of individuals to their job placements," Ms. Shultz and other Multicultural Employment Program personnel were able to provide better "outreach, employment training, and higher quality person-centered services" to the "unserved and underserved populations" in question. When the funding for the Multicultural Employment Program ended in September 1997, ARC San Francisco continued to promote the objectives of the program through "Projects with Industry," another grant-funded program that expanded service to people with disabilities from African American communities. In her testimony, Shiva Shultz said that the focus of this project is "on getting jobs for clients in minority-owned businesses." When directly questioned about the success of the project, however, Ms. Shultz admitted that ARC is having difficulty placing minority group members with disabilities in minority-owned businesses because "minority populations are not always interested in working with individuals with disabilities because the stigmas within the community make it less desirable."

Ms. Shultz's last comment suggests the entrenched nature of the barriers to employment that exist for minority individuals with disabilities, starting at the most basic level of getting access to job training and employment opportunities, followed by discrimination by employers even after someone is job-ready.

People with disabilities from diverse cultural communities still have great difficulties in finding culturally appropriate job training and career development opportunities. An overwhelming majority of the comments related to employment at the 1998 NCD hearing centered on this issue. In videotaped testimony, Rudy Stefany, a student from American Samoa, explained:

> For job training and vocational rehabilitation, I would say that I have not really seen any job training for people with disabilities. There are probably programs available, but I have not seen any people with disabilities out in the community looking for jobs or getting vocational training.... I do not know if the...private sector agencies or government departments realize the need to provide job opportunities for people with disabilities. It is very hard for us to get around and go out there and see if we can get a job for ourselves.

One hearing participant from San Francisco, Wilbert Liang, devoted his entire testimony to this subject:

> I want to point out that there are not many work-related training opportunities provided in San Francisco. We, as disabled, need to work and live. I think the government should provide more work opportunities and training courses for us so that we can rely on ourselves.

Esteban Gómez, the Latino Community Services Coordinator at the Independent Living Resource Center in San Francisco, expounded on the need for job training and work opportunities in his testimony, and offered a practical solution:

> I would like to emphasize the need for job opportunities for people with disabilities. I think it's probably one of the biggest obstacles that we face. We don't have many opportunities, and we don't have the proper training.... History

> tells us that we have a great deal of problems with getting jobs. And the ones that are actually getting jobs, they're getting jobs paid at very low wages. Mostly minimum wages, and they don't get any benefits.... The reality is that we need Congress to offer these employers some kind of an incentive so they could hire more people with disabilities. It could be tax exemptions or something.... Unless these people are willing to hire people at decent wages, prevailing wages, they're not doing anything for us.

In oral and written testimony, Mary Kwan of San Francisco echoed the need for effective job training and presented another solution to promote the economic independence of minority group members with disabilities:

> The first thing I thought is to establish training agencies. In reality, the so-called disabled have some kind of ability in many areas. By receiving training, they can have skills to support themselves. The second thing is to set up funds to loan to those who have skills, so we can carry on a small business with our ability. Just loan a small amount of money, for example, to those who can do translating and they can open up a translation service center, et cetera. This can help us to support ourselves and reduce the burden to the community, and make a new work force. They will become more confident.

Rudy Stefany also felt that promoting entrepreneurial opportunities for minority individuals with disabilities was a viable way to increase access to employment as well as visibility within the community:

> Some changes or recommendations that I would make for our community down here, I would like to see a person with a disability or a group of people with disabilities run their own business, or run their own show, in order for them to really stand out and make the community notice that we are here.

In addition, witnesses repeatedly described the failure of the vocational rehabilitation system to address minority community needs. In testimony after testimony, minority individuals with disabilities reported the difficulties they have in finding culturally appropriate job training and employment opportunities through the California Department of Rehabilitation. Hector E. Mendez, executive director of La Familia in Hayward, asserted that "rehabilitative services available to our disabled community are almost nonexistent." Judy Quan-Gant noted that even if rehabilitative services are available, they are often completely ineffective:

> I personally have been trying to get help to find a job. I've been to the California Department of Rehabilitation and they are looking down their nose at me, and just shuffling papers here and there, and not helping me at all.

According to the 1992 Amendments to the Rehabilitation Act of 1973, the inequitable treatment experienced by Ms. Quan-Gant, and by other minority group members with disabilities, has "been documented in all major junctures of the vocational rehabilitation process."[6] To address this pattern of inequitable treatment, a new section was added to the Rehabilitation Act in 1992, Section 21, which called for the establishment of a Rehabilitation Cultural Diversity Initiative to improve service delivery for minority individuals with disabilities in the state-federal vocational rehabilitation program.

Despite the addition of Section 21, the quality and quantity of vocational rehabilitation services for minority individuals with disabilities in California has declined in recent years. In July 1993, the U.S. Department of Education's Office for Civil Rights conducted a Title VI compliance review of the California Department of Rehabilitation's Vocational Rehabilitation Services Program and found statistically significant racial disparities in the delivery of vocational rehabilitation services. In response, the California Department of Rehabilitation implemented a voluntary resolution plan in December 1993 to "assess Departmental processes and policies and their impact on services and vocational goal achievement for consumers of color."[7]

To be fair, California statewide statistical reports of consumer status by race do reveal modest "improvement in successful minority client outcomes." Between 1996 and 1998, there was a 1.28 percent increase in the number of minority applicants accepted for services, and the rehabilitation rate for minority clients increased by as much as 1.72 percent.[8] When the statewide data are disaggregated, however, and the district level figures are examined, a different picture emerges. Last year in the Chico district, for example, fewer than 13 percent (12.18%) of the applicants accepted for services were minority, while almost 88 percent (87.60%) were White. Of the clients successfully rehabilitated, only 10.74 percent were minority, while 88.87 percent were White.[9] These racial disparities are also evident in the statewide closure data for fiscal years 1996-97 and 1997-98. For example, the most frequent reason cited for the unsuccessful closure (status 28) of minority clients was "failure to cooperate," but the explanation most often cited for unsuccessful closure of White clients was "other reasons."[10] The fact that minority clients are more frequently perceived as being "uncooperative" suggests that the department's interventions have not been "effective in monitoring and responding to potential service inequities," especially inequities that exist as a result of communication difficulties based on cultural differences.

Unfortunately, the ineffectiveness of the Department's interventions is perhaps most evident in the area of job training and placement services, the area that participants at the 1998 NCD hearing described as being the most problematic. According to California statewide reports on training and placement services for the 1997-98 fiscal year, minority clients received significantly less educational and vocational training and job referral and placement services than did White clients. Almost 76 percent (75.92%) of the clients who received some type of aid from the department to attend a four-year university were White, and fewer than 24 percent (23.70%) were minority. This racial disparity is consistent throughout the range of academic training provided: two-year colleges (63.71% White/ 35.82% minority); "other academic" (60.47% White/ 39.02% minority); "business school" (68.09% White/ 31.91% minority); "vocational school" (52.89% White/ 46.50% minority). Although the racial disparities are less obvious in the area of job referral and placement services, there is still on average approximately a 20 percent gap between the number of Whites and minorities receiving those services: "on the job training services" (57.13% White/ 42.58% minority); "job referral" (57.88% White/ 41.72% minority); "job placement" (57.50% White/ 42.14% minority); and "miscellaneous training" (63.50% White/ 36.10% minority).[11]

Even if minority individuals with disabilities are able to navigate through the vocational rehabilitation system and gain access to necessary training and career development opportunities, other barriers to employment still exist. It has been said that people with disabilities from diverse cultural communities face "double discrimination" because of the stigmas that society attaches to both minority group status and disability. In her testimony, Erica Li, a member of the San Francisco Chinese Blind Support Group, pointed out how this "double discrimination" can often be tripled for people with disabilities from minority communities whose native language is not English. "We are minorities," she said, but "when we look for jobs, we also come across language barriers. For example, when being interviewed for a job, we will be told that we have too much of an accent." Ms. Li added that "when they see a disabled person plus a heavy accent," employers automatically assume that the person is incapable of doing the job. They make false assumptions about the applicant's abilities in terms of their overall physical capability, and in terms of their specific language capacity. Ms. Li attributed this discrimination to fear and ignorance and suggested that "there be more education available" for employers "so that they won't be too scared" to hire minority individuals with a disability for whom English is a second language.

Regina Schneider agreed with Ms. Li in her testimony, arguing that "education needs to happen at all levels" of the employment process in order to address the whole range of barriers to employment that exist, including those faced by family members of children with disabilities from diverse cultural communities. Minority individuals with disabilities and their families stressed the need to incorporate their issues into the overall disability policy agenda.

One issue repeatedly mentioned at the hearing was the prevalent lack of access to necessary childcare for parents of minority children with disabilities, particularly after-school programs. In her testimony, Sew Gan Ching, a member of the San Francisco Chinese Family Support Group and a parent of a child with a disability, described how this lack of access to after-school programs has directly affected her ability to be gainfully employed:

> I would like to request an after-school program for San Francisco, that more kids can enter that program. Because not many kids can join the program, sometimes even though there are after-school programs available in some centers, they only take the good students, or the ones that don't need much attention. But like my son, he runs, jumps and attacks. They don't like to take him. So it is very hard for the middle, lower class people like us to get a job. In fact, I do have some abilities to work, but I have to stay at home and can't go to work. I think it is a pity. I used to be a nurse before. I haven't been able to achieve things and

> contribute to society; instead, I have to ask for resources. My son spent a lot of society's money. I don't think that is right. I want very much to work. However, if there are no after-school programs available for him, I still can't leave home to work. I feel guilty.

Jen Sermoneta, a member of the Oakland Youth Project for Inclusion of Minority, Low-Income, and Disabled Youth, cited several reasons for the lack of access to after-school programs for minority children with disabilities. To begin with, very few after-school programs are available in California for all children, let alone programs that are affordable, integrated, and accessible. In addition, the programs that meet these criteria tend to have year-long waiting lists. Existing programs are rarely staffed with employees trained to work with children of varied abilities and cultural communities. This circumstance presents a no-win situation for all parties involved, but particularly for the minority children with disabilities themselves, who end up being the true victims.[12]

In order to deal with the lack of access to child-care and after-school programs, minority parents are often forced to take drastic measures. Like Sew Gan Ching, some parents have to stay home with their disabled children and forgo valuable employment opportunities. Other parents cannot afford this option. Given the reality of their particular economic circumstances, these parents must go to work to simply feed and clothe their children. As a result, they sometimes resort to such extreme measures as locking their disabled children in their rooms. Several people at the 1998 hearing noted this unfortunate practice. According to the testimony of Lydia Kadik-Gutierrez, these parents "are very attached to their children" with disabilities, but "the children are warehoused, or kept in rooms or closets, because (the parents) don't know what else to do with them." In his testimony, Antonio Valdillez, a member of the board of directors of the Golden Gate Regional Center, stressed the need to ensure that minority parents have the option of sending their children with disabilities to a "good and safe place." Otherwise, he said, "there will still be parents that keep their sons and daughters locked in their rooms.... To me, that's unbelievable. We are almost in the year 2000, and there are still disabled people locked up in their rooms wasting away." Mr. Valdillez held everyone at the hearing accountable for this situation, including himself and the members of NCD, "because you are letting this happen." When the employment needs of minority individuals with disabilities and their families have not been met, it is disabled children who have suffered as a result. The fact that minority parents feel they must lock their children with disabilities in a room because they cannot gain access to affordable, integrated, and accessible childcare indicates the desperation of their situation. It also underlines the urgent need for action to address barriers to employment.

In addition to the employment barriers noted (the lack of job training, the language barriers, and the lack of access to childcare), minority individuals with disabilities and their families must contend with the employment barriers faced by all people with disabilities, regardless of race or ethnicity. The barriers most frequently mentioned at the 1998 hearing were Social Security work disincentives, lack of physical and architectural access to places of employment, and failure to provide reasonable accommodations in the workplace.

### Recommendations

It is clear that people with disabilities from minority communities still have tremendous difficulty gaining access not only to appropriate training and career development opportunities, but also to a host of additional employment resources that are often available to the larger community. To address these barriers, NCD recommends the following action:

- The Department of Labor, the Small Business Administration, and the Department of Education should expand funding for culturally appropriate job training and career development opportunities, and should require all federally funded programs to demonstrate their ability to meet the language, cultural, and disability needs of all populations in their service area.

According to witnesses at the 1998 hearing, one of the main barriers to finding appropriate job training and career development opportunities is the failure of the vocational rehabilitation system to address minority community needs. It is evident from testimony and data reviewed that in spite of the Rehabilitation Cultural Diversity Initiative started in 1992, significant racial disparities continue to exist in the delivery of vocational rehabilitation services. In California, these disparities are particularly apparent in the areas of job training and placement services. To change these disparities and improve service delivery for minority individuals with disabilities in the state-federal vocational rehabilitation system, NCD recommends that the following actions be taken:

- The Rehabilitation Services Administration should address the racial disparities apparent in the vocational rehabilitation system, particularly in the areas of job training and placement services.
- RSA should expand long-term funding for culturally appropriate job training and career development opportunities.
- RSA should strengthen and increase the number of interventions outlined in Section 21 of the Rehabilitation Act, which requires vocational rehabilitation agencies to take action to better address the needs of underserved groups within their service areas.
- RSA should conduct compliance reviews of all state departments of rehabilitation to determine the extent to which their efforts to comply with Section 21 of the Rehabilitation Act have produced better outcomes for people with disabilities from diverse cultural backgrounds in their states.
- The Small Business Administration, working with the Presidential Task Force on Employment of Adults with Disabilities, should provide more entrepreneurial opportunities for people with disabilities from diverse cultural backgrounds to promote economic independence.
- Federal, state, and local policy makers should incorporate the unique needs of family members of individuals with disabilities from diverse cultural backgrounds into the larger disability policy agenda, particularly in the area of employment.

NCD applauds the efforts of the Department of Education to fund and support the creation of culturally appropriate job training and career development opportunities for minority individuals with disabilities.

NCD encourages other governmental agencies to follow the example set by the Department of Education, and promotes the replication of model projects. Shiva Shultz, director of the Multicultural Employment Program of the ARC of San Francisco, suggested that an integral part of the program's success is interagency collaboration. By working directly with the Golden Gate Regional Center and with the Department of Rehabilitation, she said ARC was able to "better match the cultural needs of individuals to their job placements, and provide...higher quality person-centered services." NCD encourages such inter-agency collaboration in order to improve job training and career development opportunities for minority individuals with disabilities.

Although interventions provided in Section 21(a) of the Rehabilitation Act are substantial, efforts to deal with Section 21(b) have been less than adequate. "Preparing minorities for careers in vocational rehabilitation, independent living, and related services" is an obvious way to improve vocational rehabilitation services for minority individuals with disabilities, but it should not be the only intervention explored. As the California example illustrates, the racial disparities apparent in the vocational rehabilitation system are probably not going to be addressed without scrutiny. Legislative requirements of compliance and accountability should be incorporated into Section 21, in addition to several other interventions in the areas of outreach, language, and communication.

The racial disparities documented in the California vocational rehabilitation system are not unique to the state. They have been found in several other state vocational rehabilitation programs (Ross and Biggi, 1986; Walker, Saravanabhaven, Williams, Brown, and West, 1996). Given the nationwide presence of these inequities, and the failure of Section 21 to address them adequately, NCD recommends that the U.S. Department of Education's Office for Civil Rights conduct Title VI compliance reviews of the Vocational Rehabilitation Services Program of every state department of rehabilitation. Each department should be investigated to determine the level and quality of vocational rehabilitation services being offered to minority individuals with disabilities. If racial disparities are found, states should be required to develop and implement a resolution plan similar to California's Action Plan to Provide Racially Equitable Vocational Rehabilitation Services. This resolution plan should identify the main problems and issues in the state and outline specific interventions designed to address those issues. If any state does not implement its resolution plans, measures should be taken to make the state accountable, including the possibility of suspension or termination of Federal financial assistance.

Testimony presented at the 1998 NCD hearing indicated that minority individuals with disabilities still lack economic opportunity and, particularly, entrepreneurial opportunities. One witness at the hearing suggested the solution that Congress allocate funds to be loaned to minority individuals with disabilities who are seeking to start their own businesses.

Several witnesses at the 1998 NCD hearing testified they confronted discrimination when trying to obtain employment, not only because of their disability but also because of their perceived lack of language capacity. One witness felt that this "triple discrimination" is the result of fear and ignorance, and suggested that "there be more education available for employers." Several other respondents echoed this suggestion.

Unless a certain level of English language capacity is "an essential function of the job," minority individuals with disabilities who speak English as a second language should not be denied employment simply because of a heavy accent or a visible physical disability. There is need for further investigation and enforcement by the Equal Employment Opportunity Commission.

One of the major themes that emerged from the testimony presented at the 1998 hearing was incorporating the issues of family members of minority individuals with disabilities into the larger disability policy agenda. One issue repeatedly mentioned at the hearing was the lack of access to necessary childcare, particularly after-school programs, for parents of minority children with disabilities, with the result that a number of children with disabilities are locked in their rooms at home because parents believe they have no other options.

To address this situation, NCD recommends that the following actions be taken:

- The Department of Justice should give a high priority to investigations to assess compliance with Title III access mandates among social service center establishments serving children.
- The Department of Education and the Department of Justice should set a high priority on investigations of school district compliance with IDEA least restrictive environment requirements in the implementation of district-provided after-school programs.
- Congress should appropriate funding to increase the supply of accessible, affordable, and integrated childcare and after-school programs, and it should require that all federally funded programs meet the language, cultural, and disability needs of their entire service populations.

- The Department of Education should launch a nationwide outreach campaign aimed at informing parents of minority children with disabilities of the childcare and after-school program options available to them. Parents need immediate and direct access to information in bilingual and alternative formats on the availability of accessible, affordable, and integrated childcare in their area.

### b) Public accommodations

According to Section 302(a) of the Americans with Disabilities Act, "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation."[13] In spite of this sweeping access mandate embedded in federal law, access to public accommodations is nearly as elusive today as it was when it was defined as a major problem for minority individuals with disabilities at the 1992 NCD hearing in San Francisco.

Although Title III of ADA requires that places of public accommodation remove architectural barriers in existing facilities when it is "readily achievable" to do so, several participants at the 1998 NCD hearing testified about the continued lack of architectural access to places of public accommodation. In videotaped testimony, Rudy Stefany, a student from American Samoa, noted:

> There are major problems for accessibility to public places..., especially for stores and buildings in the private sector.... As for the government, I would say they are not really into processing the required modifications even though some work is being done.... However, there are still some people who still do not understand that we are not disabled and that we are people, human beings.

Judy Quan Gant agreed with Stefany's comments in both written and oral testimony, and provided a personal illustration:

> It's not enough for us to be in a wheelchair and have a speech impairment problem, and then go to this place and that place that is not accessible at all. We have a right to do our own shopping; we have a right to eat in any restaurant once in a while when we feel like it. Why is it so impossible? For example, the market I used to go to put ice bins in front of their meat and seafood cases, the full length of the aisle. At the far end of the aisle was a pallet of beer. I used to be able to make a left turn around the pallet and get out of the far end of the aisle. But with the new ice bins, I couldn't get out, as the wood on the pallet stuck out too far, and cut off my exit. I don't understand why some humans discriminate against other humans. We all are human beings, whether we are in a wheelchair or not, or blind or not.... I don't feel that anyone who opens their door for business should look down their nose at the poor or disabled people.

Erica Li, a member of the San Francisco Chinese Blind Support Group, testified that store owners in Chinatown routinely "look down their noses" at people with disabilities by expanding their stores out onto the sidewalk with no concern for the safety and accessibility needs of people who are blind or visually impaired:

> Stores are expanding their spaces, not only in the front but also at two sides; one side along the curb where the cars are parked, the other side in the front part of the store. So the road becomes very narrow in the middle. They don't pay attention to you. You won't be able to look or see. So it is very hard for us to walk around and people can easily hit us. If you touch their stuff, they will curse you and you will feel painful. I hope the government will regulate those stores in Chinatown so that we could move around Chinatown comfortably.

Ms. Li's concluding remark gets to the heart of the problem: a prevalent lack of implementation, regulation, and enforcement of the existing access mandates included in Title III of ADA. In videotaped testimony, Lourdes Mugas-Talan, an independent living specialist at the Hawaii Centers for Independent Living, also attributed the continued presence of architectural barriers in Hawaii to this lack of enforcement: "I always encounter architectural barriers and I know that we have ADA..., but ADA is not really enforced tightly or very well.... So, hopefully if the federal people are listening to this, they should take extra steps in the enforcement of ADA." Mariano Camacho, a member of the Governor's Developmental Disabilities Planning Council in the Commonwealth of the Northern Marianas Islands, provided an additional explanation for the persistence of architectural barriers in places of public accommodation:

> I had the opportunity to work with the Council in implementing the requirements of ADA. We did a lot of changes as far as architectural barriers are concerned. But as of this date, I can say that we need more for accessibility.... As we all know, the accessibility changes mainly concern expense. So, I guess that is why the changes are very slow on the island. But maybe if we get more assistance, people will be more willing to do the changes.

Amy Marsh, president of the Environmental Health Network of California, testified that the issue of access to public accommodations for some people with disabilities "is more complex than common questions of accessibility and the implementation of the Americans with Disabilities Act." No matter how well ADA is implemented, regulated, and enforced, for example, minority individuals with multiple chemical sensitivity or environmental illness will still have difficulty getting into public accommodations because the modifications required to accommodate these particular disabilities often fall outside the scope of what is considered "reasonable" under ADA. According to Section 302(b)(2) of ADA, a public accommodation must make reasonable modifications in its "policies, practices, or procedures" in order to accommodate individuals with disabilities; but modifications are not required if they would "fundamentally alter" the nature of the "goods, services," or operations of the public accommodation.[14] In her testimony, Amy Marsh noted that people with multiple chemical sensitivity or environmental illness often need reasonable modification in the form of access to stores that carry "safe products." "But I would be willing to bet," she said, "that these are not sold in markets and stores in many of the lower-income neighborhoods here in San Francisco. Minority and low-income people must be given the choice of safe products in the places where they shop." In spite of this unique need, the implementing regulations for Title III specifically state that "a public accommodation is not required to alter its inventory to carry accessible or special products...for...customers with disabilities."[15] In getting access to public accommodations, minorities with underserved disabilities (such as multiple chemical sensitivity and environmental illness), for the most part, fall outside the scope of coverage outlined in Title III of ADA.

Furthermore, noticeably absent from Title III is specific reference to the language and communication needs of minority individuals with disabilities and their families who speak English as a second language, or who do not speak English at all. While the Individuals with Disabilities Education Act has specific provisions guaranteeing the right of families of disabled children to a language interpreter and language-specific materials when needed, the only reference in Title III approaching accommodation is in the regulations requiring that public accommodations "provide auxiliary aids and services when they are necessary to ensure effective communication with individuals who have a hearing, vision, or speech impairment."[16] Nowhere in the statute or regulations does it specifically state that public accommodations must provide auxiliary aids and services to ensure effective communication with family members of minority individuals with disabilities who speak English as a second language. Nor does the statute or regulations require public accommodations to provide auxiliary aids and services to ensure effective communication with minority individuals with disabilities who speak English as a second language and do not have a hearing, vision, or speech impairment. The use of "qualified interpreters" is considered an appropriate "auxiliary aid and service" under ADA, and the implementing regulations specifically state that "qualified interpreters" are "an example of an auxiliary aid and service for individuals who are deaf or hard of hearing." The regulations do not state that a qualified interpreter is an auxiliary aid and service for minority individuals with disabilities other than a hearing, vision, or speech impairment (or their family members), who may not need a sign language interpreter, but rather a Spanish, Chinese, or other language interpreter.

According to the testimony of Ming Quan Chang, a family and child advocate at Cameron House (a nonprofit organization located in Chinatown), the absence of any specific language in ADA that speaks directly to this issue has had a profound impact on the ability of one of her clients to get necessary medical care for a child with a disability:

> I have a client, and she is a single mother. She has to take care of her nephew. She is one of the boat people coming from Vietnam to here in 1990, and her nephew is a special needs child.... She experienced getting very limited resources for her nephew. She has a phobia to go to the hospital because she said that she has to wait at least four hours to get a translator, to get the services. Usually she has to wait at least four hours, and sometimes she cannot get a translator at all. She waits six hours or spends her whole day in the general hospital, and she has to be rescheduled to come back the next few weeks. So right now, she refuses to go back to the hospital to do the tests for her nephew.... And she's a Chinese-Vietnamese and she does not read or write Chinese or Vietnamese at all, so it is right difficult for her, even though she has a translator, to translate exactly from what the doctor or nurse told her, so she has a difficulty to understand because there's a cultural gap among Chinese, Vietnamese, and American culture.

With ADA, if a minority individual with a disability cannot learn English as a direct result of his or her disability (such as a learning, developmental, or mental health disability), a case could be argued that the person needs a language interpreter and language-specific written materials to ensure "effective communication." The law overlooks cases like the one mentioned above, however, where a family member of a person with a disability (without a hearing, vision, or speech impairment) speaks a language other than English or ASL, and is in need of immediate access to a language interpreter in order to provide necessary health and medical services for the individual with a disability. As Hector E. Mendez, executive director of La Familia in Hayward, noted in his testimony:

> The Council bears a serious responsibility in advocating and raising the issue that ethnic minority families, whose primary language is other than English, need protection. IDEA has recognized this and has included specific language to support the uniqueness of such populations. The Council should address this issue head on.

Thus, although minority individuals with disabilities and their families face the same barriers as other people with disabilities in getting access to public accommodations (such as the continued presence of architectural barriers from a lack of regulation and enforcement), they also have unique needs that are, for the most part, outside the scope of coverage outlined in ADA. As Amy Marsh noted in her testimony, these issues are obviously "more complex than traditional questions of accessibility and the implementation of the Americans with Disabilities Act." They are complicated by a variety of serious gaps in the legal protections afforded minority individuals with disabilities and their families in gaining access to public accommodations.

Witnesses at the 1998 NCD hearing cited additional difficulties, including a lack of architectural access to restaurants; difficulty getting into accommodations necessary for professional examinations; a limited number of accessible recreational facilities; the failure of public accommodations to provide information in alternative formats; requirements for receipt of services that are tied to the use of medication for people with psychiatric disabilities; and cultural difficulty getting into same-sex bathrooms for parents of children with disabilities.

## Recommendations

To address the persistent barriers that exist for minority individuals with disabilities and their families in getting into public accommodations, NCD makes the following recommendations.

- Congress should require federal enforcement agencies such as DOJ, EEOC, DOT, and HUD to demonstrate their effectiveness in serving people with disabilities from diverse cultural backgrounds.
- Federal enforcement agencies should work together to develop a multi-agency outreach and technical assistance strategy that would constitute a national campaign to increase knowledge of civil rights protections and how to file complaints among protected communities, focused on underserved groups such as language, racial, and ethnic minorities, Native Americans, youth, and rural residents with disabilities, and their families.

- Congress should ensure that civil rights enforcement agencies have adequate financial and staffing resources to effectively address the needs of their entire service areas.

- Congress and the Bureau of Indian Affairs should provide federal financial support and assistance for the development of tribal disability rights legislation.

Effective regulation and enforcement of the public accommodation provisions of ADA is critical to addressing the unique needs of people with disabilities from diverse cultural backgrounds.

In addition to minority individuals with underserved disabilities and their families, another group largely excluded from coverage under ADA is Native Americans with disabilities living on tribal lands. As noted in a report produced by the Congressional Research Service, "The Possible Applicability of the Americans with Disabilities Act to Indian Tribes," for the most part ADA "specifically excludes Indian tribes from its requirements."[17] "Title I of ADA," the report states, "expressly excludes Indian tribes from its definition of employer," but "none of the other titles mentions Indian tribes."

This leads to a confusing and difficult situation for Native Americans with disabilities, who are largely left with no legal protection on the basis of disability, particularly in the area of public accommodations. "While Title III appears to be applicable to Indian tribes," says the report noted above, most tribes "may be immune from suits to enforce Title III's provisions by application of tribal sovereign immunity." Furthermore, only one tribal government of the 143 surveyed for a study by the American Indian Disability Legislation Project reported adopting ADA.[18]

Several other tribal governments in the survey said that while they have discussed access and employment issues, they do not have a written policy. Most tribes lack the financial resources to mount a systemic effort to build tribal disability legislation. State governments have little responsibility and even less authority on reservations. While some foundations have interest in supporting tribal development, they tend to focus narrowly on special issues or support only a few tribes. Only the Federal Government has the combination of authority, resources, and responsibility in this area. Unfortunately, no federal agency has the duty to assist tribes in addressing this gap in disability law and policy.

### c) Transportation

Although minority group members with disabilities have many problems with public transportation, the primary issue emerging from the testimony was a perceived unwillingness on the part of public transportation personnel to implement existing laws and policies and to accommodate minority individuals with disabilities. Chan Y. Yu, a member of the San Francisco Chinese Blind Support Group, testified that this is a continuing problem for people from minority communities who are blind or visually impaired:

> When we get on the bus, if there are too many people, even though there is a public notice on seating the disabled first, people don't give up their seats, especially those young people. The drivers don't say a thing. They should talk out and ask people to give up their seats. Once, I came up and nobody said a word, neither did the driver. I couldn't reach the handle bar. I almost fell down when it started to move. If, indeed, I fell and got hurt, who could have been responsible for it? So I hope the government will keep on telling people...even though there have been some public notices. The drivers should be told to tell people to help those disabled. Everyone can tell those who are in the wheelchair are disabled, but many people will kick the canes of the blind till they are broken. So this is a problem. It has caused us a lot of pain. We, the blind, only know it ourselves.

Erica Li, another member of the San Francisco Chinese Blind Support Group, echoed this sentiment:

> I couldn't agree more with Mr. Yu about the problems in public transportation. I am a blind person myself. A lot of times, when I get on a bus, the driver pushes me to the side instead of looking around and trying to find me a seat or finding me a safe place to stand. At that time, I was thinking that I wouldn't bother him if I could just find a seat or a safe place myself. I sometimes wonder if the drivers knew about the law that they were responsible for helping

> the blind to find a seat. Even if there is none, they should guide them to a safe place to stand.... When I didn't know the road, I would ask the driver to remind me to get off. Some will say yes or some only nod their heads without making a sound. Some may take you back if you miss the stop. Some can care less. Even sometimes, I asked him to stop and he didn't respond, then he told me to find my own way. At that time, I thought to myself that because I am a disabled person, I would ask you for a little help. I never wanted to cause inconveniences for you. However, if you don't have that kind of responsibility and would not give me a hand, that seemed too meaningless. I hope when drivers are being trained, they should be taught about the basic knowledge that they should be officially helping us.

As Marcella Murphy pointed out in her testimony, these issues "don't just affect the ethnic groups" that Mr. Yu and Ms. Li "come from," nor do they just pertain to people who are blind or visually impaired. According to Ms. Murphy, "people who have all different kinds of disabilities" are affected by this unwillingness on the part of public transportation personnel to implement existing laws and provide necessary accommodations, including children with disabilities who take public transportation to school. Gui Lan Lam, a member of the Chinese Family Support Group and a parent of a child with a disability, discussed her daughter's difficulties with public transportation:

> Because [my daughter] can't hold anything, it is very difficult for her to take the bus. When she got on, if there were a lot of people and there weren't any seats for her, then she had to stand there and couldn't hold on to things. She couldn't stand still and was bouncing around. Even if she got a seat, when it was time to get off, she couldn't stand by the door before the stop. Often she had to get off one or two stops later. My Mimi can't walk like the others. So in that case, she had to walk extra one or two stops. It makes it harder for her. I think the government should provide care for these disabled children. Give them taxi money to go see their doctors and get physical treatment. It will be easier to attend the meetings.

Elisa Lau, another member of the Chinese Family Support Group and a parent of a child with a disability, concurred with this frustration in her testimony:

> When [my daughter] goes to school, I wish some drivers would help her to get on the bus, but sometimes they don't even move. Being a parent, I would like to help her myself, but my daughter is so big and I am very small. They don't want to help and I can't blame them because I can't speak any English.

Although most people with disabilities experience some level of difficulty getting access to public transportation regardless of their racial or ethnic background, as Ms. Lau's testimony points out, people with disabilities and their families from minority communities experience even greater difficulty because of additional language and communication barriers. These problems are often exacerbated by the unwillingness of public transit officials to provide necessary accommodations and implement existing laws. According to the results of a study conducted in 1996 by the Howard University Research and Training Center, there is reason to believe that bus drivers, in particular, are "less accommodating and less courteous in minority and lower-income communities than in middle-class and upper income communities."[19]

Other barriers to public transportation for minority individuals with disabilities and their families emerged in the testimony presented at the 1998 NCD hearing in San Francisco. Individuals who live in isolated areas and rural communities are confronted with particularly daunting barriers. As Michael Collins, executive director of the California State Independent Living Council, noted in written and oral testimony:

> The barriers to travel in this state vary from the mountainous regions to hundreds of miles of desert highways in the south and east. In Los Angeles County, public transportation options that cross the entire county are limited. To require people with disabilities to travel great distances to a single location...is asking a great deal, especially if those individuals do not have their own reliable transportation available. ILCs [independent living centers] and other groups are

working at a number of levels to help enhance the transportation network in this state, but it is an effort that will probably never result in complete success.

In videotaped testimony, Phillip Ana, of the Hawaii Centers for Independent Living, discussed the impact of limited transportation options for people with disabilities living in the Pacific Islands:

> Hawaii needs a lot of things. Just about three to four years ago, we just got our accessible bus system, but that is only on Oahu, and transportation is not available on our neighbor islands. We are talking about basic things like going to medical appointments, going to dialysis, getting out.

As Mr. Ana pointed out, the lack of available and accessible transportation has a direct impact on the ability of minority individuals with disabilities to obtain other necessary resources. Michael Collins also made this observation in his testimony:

> You may also hear about problems with transportation, and how those problems impact people who need to visit doctors, go shopping, or simply visit their relatives and friends on an impromptu basis.

Another factor brought out in testimony that directly affects the ability of minority group members with disabilities to get access to resources is the inordinate amount of time they are forced to wait for transportation. In videotaped testimony, Rudy Stefany, a student from American Samoa, commented that "transportation is not a problem" for him, "except for the time that it takes to get transportation." Liu Fu Hai's testimony was:

> There is a problem with the transportation system. It takes at least six hours to see a doctor using the public transportation. Nothing we can do because we have to wait for the buses and change to different buses. Then we are late for the appointment and have to wait in a line.

Vernon Phillips, a freelance writer and musician who is blind, provided the Council with a current example of this problem in his testimony:

> I was an hour and a half late today because I, obviously, was in a place where a cab wouldn't pick me up until I finally went blocks and blocks to an area where I guess they pick up people if they call, and I got here. This may not be real for anyone else, but it's very real for me.

### Recommendations

Many factors contribute to the inability of minority group members with disabilities to gain access to transportation, including an unwillingness on the part of public transportation personnel to provide necessary accommodations and implement existing laws; language and communication barriers; limited transportation options for people living in isolated areas and rural communities; and prolonged waiting time for transportation, both public and paratransit. To address transportation barriers, NCD makes the following recommendations.

- DOT and/or DOJ should investigate the extent to which local compliance with ADA transportation requirements is influenced by race, ethnicity, and culture.
- Congress should ensure that transportation civil rights enforcement agencies have adequate financial and staffing resources to maintain an adequate presence with covered transportation entities to ensure compliance.
- DOT should make funds available for local transportation providers to furnish on-going diversity and disability awareness training for all public transportation personnel, as well as specific training on the public transportation provisions of ADA.
- DOT should create incentives for local transportation providers to increase efforts to hire bilingual public transportation personnel in service areas with high concentrations of non-English speakers.

Effective regulation and enforcement of the transportation provisions of ADA is critical to addressing the unique needs of people with disabilities from diverse cultural backgrounds.

Testimony presented at the 1998 NCD hearing suggests a major need to provide ongoing diversity and disability awareness training for all public transportation personnel. Additional training is needed to ensure that public transportation personnel are aware of the access mandates embedded in federal law for people with disabilities, as well as the accountability measures that will be undertaken in the event of noncompliance. They need to know that there are consequences for failing to honor federal access requirements, as well as rewards for success.

## C. BARRIERS TO CULTURALLY COMPETENT SERVICE DELIVERY

### 1. Overview

This chapter discusses persistent barriers to culturally competent delivery of disability-related services. Although Congress recognized the need for greater minority representation in rehabilitation occupations in 1992, efforts so far have been inadequate to address this problem. Similarly, the need for multilingual and multicultural communications with clients from minority communities has been recognized, but consistent problems remain.

NCD recommends that the Office of Special Education and Rehabilitative Services of the U.S. Department of Education increase its efforts to ensure that education and training at the local level is culturally accessible.

### 2. Analysis

The 1994 amendments to the Developmental Disabilities Assistance and Bill of Rights Act define "culturally competent" service delivery as "services, supports, or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program."[20] Since the 1992 NCD hearing in San Francisco, only very limited headway has been made in removing the barriers to culturally competent service delivery for minority individuals with disabilities and their families. According to witnesses at the 1998 hearing, substantial progress has been blocked by the recent political developments in the state. In her testimony, Eva Casas-Sarmiento, statewide outreach coordinator for Protection & Advocacy, Inc., highlighted some of these major developments, and emphasized their importance to people with disabilities from diverse cultural populations throughout the United States:

> Today I invite the members of the Council to pay special attention to California because we are the second largest state and the state with one of the most diverse populations. Because of our diversity, California laws and policies set the stage for nationwide trends and changes, especially in the area of public assistance and services to immigrants.... There are many recent major developments in California which are having a disparate impact on minorities in general, but also on minorities with disabilities in particular....What is happening in California which affects people with disabilities, and in particular minorities with disabilities?...The move toward managed care, welfare reform, the zero tolerance law, the three strikes criminal law, Proposition 187, Proposition 209, and Proposition 227.

Less than two years after the 1992 NCD hearing in San Francisco, California voters approved Proposition 187, a statewide initiative that prohibited "state and local government agencies from providing publicly funded education, health care, welfare benefits, and social services to any person that they did not verify as either a U.S. citizen or a person legally admitted to the U.S."[21] Coupled with the federal welfare reform law of 1996 and the failure of the Immigration and Naturalization Service to comply with federal law mandating reasonable accommodations, this initiative has proven to be particularly detrimental for undocumented immigrants with disabilities. According to Eva Casas-Sarmiento, the passage of Proposition 187 led to a sense of fear among many immigrants with disabilities and had a "chilling effect" on service utilization by this particular population:

> Part of Proposition 187 requires that public agencies report any person suspected of being undocumented. This has had a chilling effect and instilled fear in minority immigrants with disabilities who then do not seek services and preventive care which is desperately needed and for which they are eligible.

Manuel Vasquez, director of Mission Mental Health Services in San Francisco, discussed the implications of this "chilling effect" for minority individuals with mental health disabilities in his testimony:

> One of the major implications that we have experienced, in terms of services to the disabled Latino, is...the implication of the recent passing of Proposition 187, as well as 209....We feel that it has major implications for the population that we specifically serve in the Mission.... Because of residency requirements, not only does our population suffer from major mental illness that promotes disability, but also discriminatory policies by the state and federal government that excludes people from the help that they need....They exclude immigrant populations," particularly those populations that may be here without legal papers, from earlier access to the health care system, therefore delaying the response for earlier treatment.

Less than two years after the passage of Proposition 187, the California Civil Rights Initiative was approved by 54.6 percent of the California electorate. Also known as Proposition 209, this measure eliminated "state and local government affirmative action programs in the areas of public employment, public education, and public contracting to the extent these programs involved "preferential treatment" based on race, sex, color, ethnicity, or national origin."[22]

According to witnesses at the 1998 NCD hearing, this ban on affirmative action programs in the state has had a direct impact on the outreach to, and representation of, minority individuals with disabilities in disability service professions.

Eva Casas-Sarmiento spoke to this impact: "Affirmative action policies helped providers of services for people with disabilities recruit not only trained and experienced people, but also persons who were culturally competent in language ability and life experience." With the passage of Proposition 209, however, it became illegal for providers of services to people with disabilities to conduct targeted recruitment, outreach, and hiring of women and minorities. The result was that the strategy developed by NCD in 1993 to remove barriers to culturally competent service delivery by increasing minority representation in disability service professions, and improving culturally appropriate outreach, was rendered ineffective in California.

Another prong of NCD's earlier strategy, addressing the language and communication needs of minority individuals with disabilities and their families, also proved to be largely ineffective in California as a result of the controversy in the state over the issue of bilingual education. Title VI of the Civil Rights Act of 1964 guarantees the right of limited English proficient (LEP) children to an equal education. In 1974, this right was upheld by the Supreme Court in *Lau v. Nichols*, in part as a result of the tremendous activism of the San Francisco Chinese community. The Court ruled that children who were limited in their ability to speak, read, and write English were deprived of equal treatment when the schools failed to meet their linguistic needs.[23]

A little more than 20 years after this ruling, the controversial "English for the Children" initiative was developed in California, which was overwhelmingly approved in the June 1998 primary election by a 61 to 39 percent margin. This initiative, better known as Proposition 227, virtually eliminated bilingual education in California for the state's 1.4 million limited-English-speaking children, who represent more than half of the national total. Specifically, it established a statewide system of English-immersion instruction for limited English-speaking students that is mandated to last no more than one year. After the one year limit expires, children with limited English-speaking skills are required to participate in mainstream classes.[24] According to witnesses at the 1998 NCD hearing, this policy has serious implications not only in terms of the overrepresentation in special education of children from diverse cultural populations, but also in terms of the public's willingness to accommodate minority individuals with disabilities and their families who are limited- or non-English speaking.

In his testimony, Hector E. Mendez, executive director of La Familia in Hayward, noted:

> These perverse laws and initiatives have eliminated any possibility of inclusion to improve the quality of our lives. The effects of such policies are creating a sense of terror among many Latinos and very much among families with children and adults with disabilities.

Eva Casas-Sarmiento further noted in her testimony that all of these policies have had a "disparate impact on the lives of minorities in general," but they have also had a particularly "negative impact on the lives of people with disabilities who are from traditionally underserved communities and are in need of culturally competent services." For this reason, she warned NCD "to pay special attention to the situation in California" because "California laws and policies set the stage for nationwide trends and changes." According to California state librarian Kevin Starr, "California is the prism through which the United States is glimpsing its future."[25] If this is the case, recent political developments in California have ramifications in terms of service delivery for minority individuals with disabilities throughout the United States. An example is a measure passed the U.S. House of Representatives on September 10, 1998, that placed strict limits on bilingual education in the entire United States. This can be interpreted as a direct result of California's Proposition 227 and a clear indication that California is truly "the prism through which the United States is glimpsing its future."

Fifty-two percent of the participants at the hearing testified about their difficulties in getting culturally competent services resulting from the lack of minority representation in disability service professions. More than 42 percent testified about the inadequacy of culturally appropriate outreach efforts. Another 40 percent discussed the failure of disability service providers to address the language and communication needs of minority group members with disabilities and their families. These testimonies illustrate the strength of the barriers that continue in culturally competent service delivery, particularly in the areas of representation, outreach, and language.

### a) Minority Representation in Disability Service Professions

Among the primary barriers to culturally competent service delivery identified at the 1992 NCD hearing was the lack of minority representation among disability service personnel. To address this situation, NCD called for an increase in the number of minority individuals working in disability service professions. Responding to this issue in 1992, Congress added Section 21, "Traditionally Underserved Populations," to the Rehabilitation Act of 1973. Through Section 21, Congress hoped to improve the delivery of culturally competent services to minority individuals with disabilities in the state-federal vocational rehabilitation program by mandating the creation of interventions that would increase the number of minority professionals working in vocational rehabilitation, independent living, and related services. Despite this mandate from Congress, minority group members with disabilities and their families still face barriers to culturally competent service delivery because of the shortage of disability service professionals from diverse racial and ethnic communities. In testimony at the 1998 NCD hearing, Nicole Brown-Booker commented on this lack of minority representation in the field of disability counseling services:

> I work in an agency that provides counseling services for...parents with disabilities, and one thing that really stands out for me is that none of the clinicians...and only one of the therapists on staff is a person of color.... I've just finished my graduate work, and I'm going to be a therapist...but I haven't been able to find other people who do the work that I do, that work with clients that have disabilities that are people of color.... I feel like I'm the only person out there who looks the way I look, and is working with...this particular population.

Rudy Stefany, a student from American Samoa, offered a client's perspective in videotaped testimony. He noted the tremendous need for "more counselors and people that really understand what people with disabilities are going through." An unidentified Asian woman agreed with this sentiment in her testimony. "There's a shortage of culturally appropriate counseling," she said, "and I'm in dire need of counseling that's bicultural.... I'm stressed out because I don't really want to bare my soul to someone who doesn't understand both sides of where I came from." Phillip Ana, of the Hawaii Centers for Independent Living, understood this need for cultural identification between clients and disability service providers, particularly in the mentoring process:

> When we talk about vocational rehabilitation, what would be helpful is to have someone who is a minority. I think the biggest thing that helped me was to have a model to look at—someone to identify with and say, "He did it or she did it, and so can I." I had individuals to look up to and it made a difference.... When working with someone in Samoa, you need to speak the language and show

> people of the same culture who have had success.... Find someone who lives in my community, I know his family. If he can make it, I can make it.... It's hard to teach someone from a minority culture about advocacy unless you do it in terms that are understandable.

In an 1991 article, "Goals for Improving Services to Minority Individuals with Disabilities," Robert R. Davila, former Assistant Secretary for Special Education and Rehabilitative Services of the U.S. Department of Education, also noted the importance of cultural identification in mentoring minority children with disabilities:

> Minority students are directly and positively affected by the presence of minority teachers in the classroom. Children with disabilities from minority backgrounds need role models every bit as much as other children. I know this from personal experience. During the entire time I was a student, from elementary school through graduate school, I was never taught by a teacher from a minority background. Indeed, there was a time in my life when I actually believed that an individual with a minority background could not be a teacher.[26]

Today, minority children with disabilities in California might come to a similar conclusion given the racial and ethnic composition of special education teachers in the state. Eva Casas-Sarmiento testified that a "number one concern" for "minorities with disabilities" is the "lack of special education teachers, counselors, aides, therapists, and other providers who speak their language and understand their particular needs unique to their life experience, culture, or race." Nancy Lim-Yee, a health worker at the Chinatown Child Development Center in San Francisco, also expressed concern that "there are few bilingual/bicultural school personnel in all areas of special education, including teachers, paraprofessionals, school psychologists, speech and language specialists, physical/occupational therapists, etcetera." Statewide special education data validate this concern.

According to the Special Education Statewide Enrollment Reports from April 1998, more than half (57%) of the students enrolled in special education in California are from minority communities. Even so, fewer than 15 percent (14.9%) of the special education teachers in the state are minority, and almost 85 percent (84.3%) are White.

Nancy Lim-Yee testified that this racial and ethnic imbalance among special education teachers and students with disabilities in California leads to "conflicting expectations and poor parent-teacher communication":

> Parents are not able to communicate on a regular basis with their children's teachers in order to work together for the benefit of the children. Thus parents do not get the information they need, and teachers are frustrated with the lack of follow-through and support. The child often ends up blamed, shamed, and isolated.

These communication problems are often compounded when parents of children with disabilities live in isolated areas and rural communities. Because of the transportation barriers in rural communities and the lack of available language interpreters, these parents have extreme difficulties communicating with the special education teachers in their area, who are usually White and monolingual.

To address this specific concern, California State University at Chico launched an aggressive teacher training program in 1994 designed to prepare bilingual university students from traditionally underrepresented ethnic groups, and students with disabilities, for careers teaching special education in rural California school districts. This project, called "Meeting Changing Rural Needs," placed an emphasis on meeting the unique needs of culturally and linguistically diverse special education students. Through a grant from the U.S. Department of Education's Office of Special Education and Rehabilitative Services, the program in four years has offered substantial financial assistance to 29 students from minority communities, 15 of whom are now employed as teachers in California public schools. Because of programs such as this, California is beginning to see an increase in the number of bilingual/bicultural special education teachers, but the numbers still fall well below the need. Nancy Lim-Yee contends that the most effective way of meeting this need is to "mandate recruitment and hiring of bilingual and bicultural staff at all levels."

One level of the special education system in California that could benefit from targeted recruitment and hiring is mediation and due process. In her testimony, Beverlyn Lee, a special education advocate and a parent of a young man with a disability, pointed out the lack of minority representation among special education mediators and hearing officers:

> I would like to share with you one example of institutionalized racism perpetuated by our special education service delivery system. As a special education advocate I have represented many families of color in mediation and statewide administrative hearings. There are no mediators or Special Education hearing officers of color, particularly African Americans. As we approach the new millennium, we seem to be no further away from the "Jim Crow" laws that limited our personal freedom. There is no justification for the lack of diversity at this level. The not so subliminal message is that Anglo Americans still make all the decisions with respect to our lives.

Ms. Lee's testimony was a shock to most of the participants at the hearing. After she presented her testimony, one NCD member asked, "Am I understanding you to say that at the state mediation level within special education, in a state such as California, there are no mediators...of any color?" "Not that I know of," Ms. Lee responded. "Not at the mediation hearings that I have represented parents at. There's no one of color, and particularly no African Americans."

NCD discovered that Ms. Lee's findings are accurate. According to Glenn Fait, the director of the California Special Education Hearing Office at McGeorge School of Law, there are no special education mediators of color in the state, and only three of the eight hearing officers are persons from minority communities. Furthermore, as Ms. Lee contended, no special education mediators or hearing officers in California are African American.

When questioned about the outreach and recruitment efforts conducted by the California Special Education Hearing Office, an official of the Institute for Administrative Justice at McGeorge School of Law reported that announcements are routinely made at the Special Education Advisory Committee when there are vacancies for mediator positions. This committee is composed of representatives from several disability organizations, including

Protection & Advocacy, Inc., and the Disability Rights Education and Defense Fund. Because special education hearing officers are required to have a Juris Doctorate degree, recruitment for these positions is limited to advertisements in legal newspapers and announcements on the Internet. The California Special Education Hearing Office does not conduct targeted recruitment of specific racial and ethnic groups, nor are any specific efforts made to hire people with disabilities. Of the 15 mediators and 8 hearing officers, only one mediator is a person with a disability, and that person is not a member of a racial or ethnic minority group.

This raises another issue of representation that is largely overlooked in the discussion about culturally competent service delivery: the lack of disability service personnel who are not only members of racial and ethnic minority groups, but also people with disabilities. That someone is bilingual or bicultural does not necessarily mean the person will understand or be sensitive to the needs of people with disabilities from minority communities. This is a particular problem given the stigmas attached to disability within various cultures. A member of the Chinese Family Support Group made this point in her testimony:

> We have applied for SSI...at the branch office of SSI in Chinatown. This woman cursed us. She has cursed 99 percent of the Chinese who went there. She does things differently according to the situation.... She has the worst attitude.... I hope these things could be noticed, and pay attention to the social worker's attitudes. We don't like to have disabled people at home, but we don't have any choices.

In his testimony, Li Yu Lan of the Chinese Newcomer Support Center noted that generational differences and immigration status further complicate this issue:

> I have come across some problems when dealing with the Social Security bureau. There is a group of Chinese who work at the bureau at Kearny Street in Chinatown of San Francisco.... The people that work there asked me how many years I have worked in mainland of China. I said almost 38 years. They thought I must have retirement. I said I didn't have that. They asked me to get a certificate from them. I said you people in America have no idea about how it works in

> China. They are hoping you would have died. They won't write anything for you. I said it is impossible to obtain one. They insisted if I don't provide a certificate, they won't be able to help me. I was trying to explain to them the situation.... A few months later, the dismissal certificates of my wife and children were here, but I still didn't receive mine. So I wrote a letter to the mainland. After another few months, they finally sent me one. I submitted it to the Social Security bureau, but they wouldn't believe me.... I think the bureau was intended to be set up in Chinatown so that it could provide help for the Chinese. On the contrary, we experienced problems.... They should be more careful about who they choose and find people who are ready to serve.

Thus, generational differences among immigrant groups can further complicate service delivery. Even if disability service providers are bilingual, bicultural, and disabled, they still may not understand the unique needs of recent immigrants with disabilities if they are third- or fourth-generation Americans.

Another aspect of representation noted at the 1998 NCD hearing is the absence of minority individuals with disabilities in positions of decision-making power. Beverlyn Lee concluded her testimony by asking, "When will African Americans be able to finally sit at the decision-making table? We are ready and tired, so tired of waiting." Nowhere is this discrepancy more apparent than in the composition of the general and administrative staff for California's network of independent living centers. In his testimony, Michael Collins, executive director of the California State Independent Living Council, discussed some of the efforts being undertaken by the state's independent living centers to meet the unique needs of minority individuals with disabilities and increase their representation within the general ILC staff population:

> I am proud to point out that many of the independent living centers in California have taken positive steps in dealing with the unique needs of minority communities. Outreach offices in San Francisco, Orange County, and many other counties provide materials and services in multiple languages to meet the needs of the populations who reside there. Several offices, including Salinas, El Centro,

and Indio, provide bilingual staff members who speak Spanish to meet the needs of a booming immigrant population.

The positive results of these efforts are reflected in the racial and ethnic composition of the ILC general staff members. According to the Section 704 Report for 1997, more than 50 percent (52.34%) of the general staff for the state's independent living centers are members of minority communities, and at least 60 percent (60.2%) are people with disabilities.[27]

Elsa Quezada, executive director for the Central Coast Center for Independent Living, noted, however, that this same level of diversity is not reflected at the administrative level among decision-making staff. She said only a handful of ILC executive directors in the state are members of minority communities. The Section 704 Report, in fact, reveals that more than 60 percent (62%) of ILC decision-making staff are White.[28]

This lack of racial and ethnic diversity is also reflected in the composition of the California State Independent Living Council. Michael Collins pointed out that of the 18 current SILC members only one representative is a person from a minority community. Section 705(b)(4) of the Rehabilitation Act of 1973 requires that a majority of all SILC members be persons with disabilities. There is no similar requirement in the law to ensure minority representation.

Testimony presented at the 1998 NCD hearing indicated that minority group members with disabilities and their families experience great difficulty getting access to necessary resources in the areas of counseling and special education because of the shortage of bilingual and bicultural service providers. Some witnesses at the hearing noted that these difficulties are compounded when service providers do not have a disability or when they are three or four generations removed from immigration. Although minority representation within California's independent living centers has increased significantly over the past six years, there are still noticeable differences between the numbers of minority individuals represented at the general and administrative staff levels.

When officials were questioned about the continued shortage of minorities within disability service professions, the common explanation was that minority individuals with disabilities do not apply for these positions. This response absolves agency representatives of responsibility and implies that minority individuals with disabilities are not applying because they are not interested. The testimonies presented at the 1998 NCD hearing in San Francisco, however, indicate that the reasons for the lack of minority representation are more complicated than a simple lack of interest. Participants at the hearing felt that it had more to do with cultural barriers in society, particularly those related to culturally appropriate outreach.

### Recommendations

Based on the testimony presented at the 1998 NCD hearing, it is clear that minority individuals with disabilities still encounter significant barriers to culturally competent service delivery as a result of a shortage of disability service personnel from diverse cultural backgrounds. To address this barrier, NCD makes the following recommendations.

- The Departments of Education, Health and Human Services, and Labor should increase incentives for recruitment and education of individuals from diverse minority and cultural communities, particularly individuals with disabilities, to enter disability service professions, and to be afforded educational and professional development opportunities after entry. For example, the Department of Education should enhance funding for scholarships funded through the Office of Special Education and Rehabilitative Services to minority institutions to increase the number of qualified graduates of culturally diverse backgrounds, especially those with disabilities.
- RSA and the Office of Special Education and Rehabilitative Services (OSEP) should continue efforts to increase the number of minority professionals working in vocational rehabilitation, independent living, and related services, and they should encourage duplication of these efforts by other disability service agencies. Rehabilitation Capacity Building initiatives should be used to develop new programs in Historically Black Colleges and Universities, Hispanic Serving Institutions, Native American serving institutions, and Asian American/Pacific Islanders serving institutions that will increase the number of qualified rehabilitation personnel of diverse cultures in the system.
- RSA and other federal funders should require disability service providers to have a demonstrated commitment to workplace diversity and family-friendly policies.

Along these lines, RSA should mandate hiring of a higher percentage of graduates (RSA scholarship recipients) of the programs mentioned above each year to fulfill the Comprehensive System of Personnel Development needs of every agency.

- Congress should appropriate adequate funding to EEOC, DOJ, HUD, DOT, and DOED to enable them to provide disability rights training to people with disabilities from diverse cultural backgrounds, their family members, and bilingual individuals, with the goal of creating a core group of culturally diverse individuals in every state who can train additional individuals in the requirements of federal civil rights laws and how to use those laws when a violation occurs.
- The Department of Education should issue a policy memorandum mandating targeted recruitment and hiring of bilingual and bicultural special education staff, including staff with disabilities, at all levels.
- OSEP, along with the Office for Civil Rights at the Department of Education, should investigate the racial and ethnic composition of special education staff, including mediation and due process outcomes.
- Federal funding agencies such as Education, HHS, and DOL should encourage voluntary public disclosure of diversity data for entities receiving federal funds. In addition, federal agencies such as RSA should require an annual cultural competency assessment for every state agency and maintain a national database containing the following personnel information: position, ethnicity, gender, disability status, education, certification/licenser, and salary.
- NIDRR should fund a longitudinal study on participation of culturally diverse professionals in the rehabilitation system. In addition, NIDRR should fund research on rehabilitation outcomes, educational outcomes, and so forth, as a function of counselor/teacher ethnicity, gender, disability, education, and professional competency.

In 1992, Congress added a new Section 21 to the Rehabilitation Act of 1973 entitled "Traditionally Underserved Populations." Through Section 21, Congress hoped to improve the delivery of culturally competent services to minority individuals with disabilities in the state-federal vocational rehabilitation program by mandating the creation of interventions that would increase the number of minority professionals working in vocational rehabilitation, independent living, and related services.

The Rehabilitation Services Administration responded to this congressional mandate by implementing a series of interventions designed to meet this goal. One of these interventions was financially assisting institutions of higher education with at least 50 percent minority enrollment to prepare students for vocational rehabilitation and related service careers. Another was launching the Capacity Building Project in 1996 with the awarding of 17 grants to various educational institutions and nonprofit service agencies for the provision of outreach services to minority entities.

NCD applauds the efforts of the Rehabilitation Services Administration to increase the number of minority professionals working in vocational rehabilitation, independent living, and related services. NCD supports the continuation of these efforts and encourages other federal agencies to follow the example set by RSA.

NCD also recognizes the efforts of the Office of Special Education and Rehabilitative Services to increase the number of minority professionals working in the field of special education through the provision of educational and professional development opportunities in the form of long-term training grants. One OSERS project of particular note is the "Meeting Changing Rural Needs" administered by California State University at Chico's Special Education Department, described earlier. In order to address the racial imbalance that exists in California between special education students and staff, several witnesses at the hearing suggested that targeted recruitment and hiring of bilingual and bicultural special education staff should be mandated at all levels. Partnerships need to be established with minority community networks in order to develop a national outreach program targeting minority populations that will increase their employment numbers in the field of special education.

Two of the primary mechanisms for regulation and enforcement in special education are mediation conferences and due process hearings. In California, given the current racial and ethnic makeup of the special education mediators and hearing officers in the state, there is strong reason to believe that these methods of regulation and enforcement are not as effective for parents of minority children with disabilities (100 percent of the mediators and 62 percent of the hearing officers in the state are White). If this is the case in California, one of the most ethnically diverse states in the nation, then there is reason to believe that lack of minority representation and corresponding ineffectiveness of regulation and enforcement also exist in several other states across the nation.

NCD recommends that all federal and state disability service agencies, particularly state special education hearing offices, increase their voluntary disclosure of information related to the racial and ethnic composition of their workforces, particularly at the administrative level. Public disclosure of how well disability service agencies are expanding employment opportunities for minority group members can be an effective incentive for other disability service agencies to develop similar measures and begin a process of positive social change. The availability of this information will also assist professionals from minority backgrounds in making informed employment choices.[29]

Several of the witnesses at the 1998 NCD hearing in San Francisco recommended that specific efforts be made to increase the number of minority individuals with disabilities in positions of decision-making power, particularly within disability service agencies such as California's network of independent living centers.

All disability service agencies, particularly centers for independent living, should be required to examine their practices and procedures for promoting qualified minorities with disabilities to administrative and decision-making positions, assuming that such procedures exist. Short- and long-term objectives should be developed that aim to increase the representation of minority individuals with disabilities at the administrative level. Internal mechanisms to assess agency progress in meeting stated diversity objectives should also be implemented.[30]

Preparing minority individuals with disabilities for administrative and decision-making positions should begin early on in life. Minority youth with disabilities must have direct access and exposure to successful minority adults with disabilities occupying positions of decision-making power. Several programs across the United States are currently promoting this objective, including the Bridges to Youth Leadership 2000 Minority Students with Disabilities Mentorship Program, sponsored by the Howard University Research and Training Center for Access to Rehabilitation and Economic Opportunity; the California Youth Leadership Forum for High School Students with Disabilities, sponsored by the California Governor's Committee for Employment of the Disabled; and the annual National Leadership Development Conference for

Youth with Disabilities, sponsored by the National Council on Disability, the Department of Health and Human Services (Administration on Developmental Disabilities, Maternal and Child Health Bureau, and Substance Abuse and Mental Health Services Administration), the Social Security Administration, and the Department of Education.

The Rehabilitation Services Administration made substantial efforts to improve outreach to minority communities by launching the Capacity Building Project in 1996. The goal of this Project was to provide technical assistance and outreach to "minority entities" (minority educational institutions, minority-owned businesses, and organizations serving minority individuals with disabilities) in order to build the capacity of these entities to compete successfully for and manage RSA and NIDRR-funded grants, contracts, and cooperative agreements.[31]

Despite these efforts, minority group members with disabilities and their families are still largely unaware of the services and resources available to them. A recent study conducted by the Howard University Research and Training Center found that "persons with disabilities, especially those who are from diverse ethnic minority communities, are not sufficiently aware of the existing laws pertaining to services and opportunities for employment available to them."[32] This finding is corroborated by the testimonies presented at the 1998 NCD hearing in San Francisco. Eva Casas-Sarmiento, statewide outreach coordinator for Protection & Advocacy, Inc., testified that "in many instances, noncitizens with disabilities assumed that they could not become citizens because they did not know of laws which exist to help them become citizens, such as the waiver of the naturalization testing and oath requirements and reasonable accommodations as required by ADA." In videotaped testimony, Rudy Stefany, a student from American Samoa, noted that "getting information is a problem." "As for the Americans with Disabilities Act," he said, "there are still people who are unaware of the Act....These agencies really need to go out there and inform them of what is really going on right now." Lourdes Mugas-Talan of the Hawaii Centers for Independent Living also observed that "a lot of people" she works with "are still not aware of ADA." Another employee of the Hawaii Centers for Independent Living, Phillip Ana, provided the following:

> I live on the Windward side of Oahu and the population there includes Tongans [and] Samoans. This population, depending on where they come from, is

not aware of the issues for people with disabilities, such as accessibility and employment for their sons and daughters.

As Mr. Ana's remarks indicate, parents of minority children with disabilities have a particularly difficult time getting the information they need, especially if their native language is not English. According to the written testimony of Nancy Lim-Yee, a health worker at the Chinatown Child Development Center in San Francisco:

> For...parents who are limited- or non-English-speaking, the greatest problem is that of minimal or nonexistent access to information and resources.... Because of language and cultural barriers, parents have a more difficult time learning about and being able to exercise their rights and responsibilities. Most parents are not aware of the services available to their children through the schools, such as augmented facilitative speech services, full inclusion, adaptive technological assistance, etcetera.... They are also not aware of the resources available to them.

Noreen Ringlein, an advocate for Parents Helping Parents, a parent training and information center in San Francisco, concurred with that testimony and noted that her job is becoming increasingly difficult because "the system isn't informing parents that laws exist." Both state and federal law require that school districts provide all parents of children with disabilities with a "notice of parent rights," which must be translated into a parent's native language, if requested. This notice explains the procedural safeguards and rights afforded to special education students and their parents under the Individuals with Disabilities Education Act and the California Education Code (20USC1415; 34CFR300345; Educational Code 56321). Among these rights is the right to have an interpreter present at an IEP meeting, as well as the right to have all pertinent materials translated into a parent's native language. In spite of these legal rights and notification requirements, Ruben Rangel, a parent of a child with a disability, testified that "up until this year, I was not aware that I had the right to an interpreter, that I had a right to ask the program specialists to present...materials in my native language. I didn't know about this. I always went to the IEP alone....I didn't know that we had these rights."

Witnesses at the 1998 NCD hearing said that increasing awareness among minority individuals with disabilities would require that all outreach efforts be made in a culturally and linguistically appropriate manner, taking account of the fundamental differences between majority and minority cultures. Beverlyn Lee made this point when she asked, "When will the system learn that one must gain knowledge about others' cultures to effectively reach them? It is not enough to just tolerate us. You must know us.... If we intend to include people of color we must be sensitive to their cultural values, practices, and the context in which these practices take place." Nancy Lim-Yee noted in her testimony that effective outreach requires a recognition and understanding that "cultural differences are very real," and that these differences directly affect the ability of minority group members with disabilities and their families to get the information and services they need.

In a 1997 article, Virginia Thompson chronicled some of the fundamental differences between majority and minority cultures and discussed the implications of these differences for outreach and service delivery for minority individuals with disabilities. According to Thompson, "the U.S. majority culture, considered by some the most individualistic in the world, lies at one extreme of a worldwide individualistic-collectivistic continuum, while most U.S. minority groups have contrastingly collectivistic orientations, reflective of their respective cultural origins."[13] Thompson contends that underlying these different cultural orientations are divergent views of self, based either on independence or interdependence. The independent view of self, most often expressed in individualistic cultures, is grounded in a belief of the primacy of the individual where personal autonomy is valued and family and community are of secondary consequence, she says. Interdependent views of self, on the other hand, which are most often found in collectivistic cultures, are grounded in a belief that the social unit (i.e., group, family, tribe, clan, community) should take primary consideration over the individual.

This interdependent view of self can be found throughout most minority cultures in the United States. A 1996 article in *American Rehabilitation* points out that the concept of the extended family in Pacific cultures is basic to the nature of its people and has evolved over two centuries.[14] It says that in Samoan cultures, in fact, the aiga potopoto (extended family) is regarded as the most important agent in the human equation. Phillip Ana of the Hawaii Centers for Independent Living noted this in his testimony. "Working with someone from a Polynesian culture," he said, "is working with the family.... It's a very family-oriented culture." According to Paul Leung, this emphasis on the role of the family and interdependence is also a hallmark of many Asian cultures.[35] Jean Lin, CFILC empowerment team leader, agreed with this assertion. "In Chinese culture," she said, "we honor our family first." The primacy of family and interdependence has also been documented in Hispanic cultures. Anna Santiago and colleagues wrote in *American Rehabilitation* that "service providers need to understand the importance of the family for Latinos."[36] In her testimony, Laura Echegaray, ILRC Latino community disability educator, described the importance of family and community in Latino culture:

> Latino culture is very proud of their strong family ties.... I come from a very diverse community—4 million people in a tiny, small island, where we call ourselves a family. When I got to San Francisco, I couldn't have survived without my fellow Puerto Ricans, who have become my family, even though we are not related.... I urge you to break the barriers and see us all as a family.... We all invite you to see us as a family.

A similar invitation was issued a few years ago when a group of minority professionals with disabilities, largely made up of African Americans, assembled in Washington, D.C., and formed an organization called the National Family for the Advancement of Minorities with Disabilities.

The concept of interdependence and family is equally important in Native-American culture. Although every American Indian tribe has its own set of values and beliefs, Carol Locust and Jerry Lang have noted that one of the common concepts in most tribal groups is the importance of family, clan, and tribe.[37] Randy Feliz, vice chair of the Hopland Band of Pomo Indians, agreed with this finding. "We are a very family-oriented culture," he said. "No matter where I am, I am never alone. I meet other Indian families and they take me in, no questions asked."

The tremendous importance of family and interdependence within U.S. minority cultures is well documented in the current literature. The primacy of the individual and independence within U.S. majority culture is an equally well-established fact. Nowhere is the importance of the individual and independence more apparent than in the culture of the American disability community.

Since its founding, the disability civil rights movement in the United States has exemplified many of the values and ideals promoted in individualistic cultures, including personal independence and individual autonomy. In the early 1970s, the "independent living movement" for people with disabilities was christened in California, largely as a result of the efforts of Ed Roberts, who defined independence as "control over one's life."[38] This emphasis on independence and individual autonomy in the disability rights movement was reflected in several of the major disability policies. In 1973, the Rehabilitation Act introduced Individualized Written Rehabilitation Plans, and in 1975, what eventually came to be known as the Individuals with Disabilities Education Act was enacted. Independent living services were officially established in 1978 to help persons with disabilities to live independently.[39] In 1977, Lex Frieden, former NCD executive director and Henry B. Betts Award recipient, defined "independent living" as "control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities."[40]

Over the past decade, this emphasis on independence within the disability civil rights movement has been increasingly called into question by several segments of the disability community. Even though, as Adolf Ratzka has said, "Independent living does not mean that we want to do everything by ourselves, do not need anybody, or that we want to live in isolation," in the context of non-western cultures an excessive emphasis on an individualistic-centered definition of independence can sometimes lead to a feeling of extreme isolation. In her testimony, Nancy Lim-Yee expressed concern that for someone from a non-western culture, the American emphasis on empowerment and independence may seem like telling them to "do it yourself" and not ask for help. Virginia Thompson noted in her article that these concerns "regarding the growing emphasis on independence" are raised because "to some degree, all persons require interdependence...Full independence may not be an achievable or desirable goal since it discounts the value of interdependent relations" in our nation.[41] In his statement on ADA's final passage, Representative Major R. Owens (D-NY), also noted that "our nation is one of interdependence; we do and must rely on one another for success."[42]

In the context of interdependence found within many minority communities, terms such as "individual empowerment," "self-sufficiency," "independent living," "control over one's life," and "minimal reliance on others" may seem foreign, quite isolating, and even offensive. If an independent living philosophy and its related terms and concepts are not adequately translated and presented in a culturally appropriate manner, there is potential for conflict with the mind set of many minority communities, which emphasize the importance of family, interdependence, and reliance on others, particularly when dealing with the issue of disability. In her written testimony, Nancy Lim-Yee noted that there are significant "cultural differences...in the perception and impact of disabilities on the individual and the family."

> Most Asian and Pacific Island cultures perceive disability, especially in a child, as a reflection upon and responsibility of the family (including several generations) as a whole. The American approach tends to view disability as a matter regarding the individual and perhaps the parents (but seldom siblings, grandparents, or extended family).

The perception that disability is a family responsibility was also voiced in the testimony of Ruben Rangel, a parent of a child with a disability. "Ever since I was aware of the problem with Elizabeth," he said, "we decided it was a problem that we had to live with.... Since that moment, we became aware of our commitment, our responsibility, and our obligation." Laura Echegaray noted that even into adulthood, Latino parents "feel responsible to care and provide for the needs of their adult children with disabilities, even if they are capable to live on their own."

According to Virginia Thompson, this sense of family responsibility for disability within many minority communities stems primarily from the perception of disability that exists within collectivistic cultures:

> Collectivistic cultures tend to view both mental and physical health as manifestations of group harmony. For example, both Navajo and Chinese concepts of health are based on harmony with one's natural universe, while illness is evidence of being out of harmony, often the result of broken taboos or family rules. Accordingly, such cultures tend to see disability, especially psychological disability, as something shameful that has been visited upon the family by spiritual forces and, therefore, as the family's responsibility to manage. Such beliefs often lead to a preference for and use of nontraditional medical/spiritual

> sources that can return the person to harmony with the group, thereby resolving the problem through in-group resources.[43]

Nancy Lim-Yee agreed in her written testimony and noted the importance of culturally appropriate outreach and parent/family education:

> Disability within minority families may be perceived by the family and community as a shameful or negative reflection upon the whole family….When a child with a disability (or multiple disabilities) is born to an Asian/Pacific Islander family, that family must go through a process of identifying the situation and coping with it emotionally and practically, within a social and cultural context. They are likely to look first within the family and within their own ethnic/cultural community health and spiritual systems for help. Seeking help outside the community, especially when one doesn't know what to ask for or what is available, is likely to be a last resort and a response to crisis. At this stage, culturally appropriate and linguistically accessible outreach, parent/family education, and support are critical.

Nancy Lim-Yee's remark underscores the need for education and outreach to families of minority individuals with disabilities, as well as to minority communities, in order to provide support in dealing with the impact of disability and, in turn, increase awareness about available resources and the experience of disability. In her recommendations, she suggested that NCD "encourage local and statewide media to bring awareness of disability issues to the ethnic and general communities." Several other participants at the 1998 NCD hearing agreed and supported the idea of using the media to increase awareness about disability within both minority and majority communities. In her testimony, Lourdes Mugas-Talan stated that "there should be more public education in the media to let people know about ADA," and Rudy Stefany noted that "we need more education for people who are so-called "normal" about people with disabilities." Chan Y. Yu, a member of the San Francisco Chinese Blind Support Group, agreed with Mr. Stefany's suggestion and provided a personal example of the need for community education through the media:

> For the past few years, I haven't noticed much government publicity on the cane used by blind people. For example, I went to town using a 3-section cane. When I came to Market Street, I didn't know what had hit. A man pushed me and broke my cane. I brought it with me today. It is broken. But that man is gone. I couldn't do a thing....Currently, there is another kind of cane, and it's long and portable. It is white, red, and white, but not many people know about it. They thought you were pretending to be blind...so I think the government should let the public know about the white cane used by the blind. We hope the public will know more about blind people.

Another member of the San Francisco Chinese Blind Support Group concurred with Chan Y. Yu. "We use a...cane," she said, "and no one can see that, especially the White people. There is so much trouble. I hope the government will use more media to educate people so that the blind can have some conveniences."

As Leroy Moore noted in his testimony, however, it is not enough to simply use the mainstream media. To reach minority group members with disabilities and their families effectively, he said, and to increase awareness within minority communities, targeted advertising must be conducted in minority media:

> We have to question why this conference and other disability events are not published in minority magazines and newspapers like the *Sun Reporter*, the *Bayview San Francisco*, and *Asian Weekly*.... The Bay Area has a lot of ethnic minority media, and if you want the involvement of ethnic minorities, you have to advertise in minority media.

David Freeman, of the San Francisco State University Institute on Disability, strongly agreed with this recommendation. He noted the additional importance of directly involving minority community groups and churches in the outreach process:

> Extensive outreach methods should be adopted. New ideas should be implemented to ensure everyone in a community knows about resources and/or

> services. Churches, recreational facilities, etcetera, should be contacted and brought into the process simply because many minorities still hold these institutions very important to daily life.

Elsa Quezada, executive director of the Central Coast Center for Independent Living, also noted the importance of "developing partnerships with community groups and churches." "The community must be your office," she said. "In order for outreach to be effective, you have to be committed to going out into minority communities and distributing information in places frequented by minorities." One program that has had success in this area is Black Pearls in Brooklyn, New York. To increase awareness about breast cancer, Black Pearls distributed information through 111 beauty shops in the community frequented by minority women. One of the beauty shops runs a video about breast cancer on a small television set and encourages customers to fill out questionnaires measuring their knowledge of breast care as they have their hair done. The owner of the shop receives 50 cents per questionnaire and $100 per month for providing this outreach.[44]

According to Nancy Lim-Yee, the need for education and outreach does not go in one direction only. Awareness about disability issues needs to be increased within minority communities, but there is an equally profound need to increase awareness about minority cultural issues within the disability community. While "the ethnic community agencies often know little about disabilities," Ms. Lim-Yee said, "the mainstream" disability organizations know even less about how to be "culturally and linguistically accessible." Mark Wilkerson of the California Foundation for Independent Living Centers agreed with this point in his testimony. "I feel like the disability rights movement suffers from 'isms,'" he said. "Racism, sexism, and not a whole lot has really changed since the outset." Nicole Brown-Booker echoed this sentiment in her testimony:

> The main issue I would like to talk about is the inclusion of people with disabilities within disability organizations themselves. I've been working in the disability community for about three years now...and have always felt that there wasn't anybody else out there that looked like me. Even in the disability organizations that I've been a part of since I moved to Berkeley, there aren't a lot

> of people of color represented within those organizations. I believe the movement has taken on issues of people with disabilities to be included in society, but has not necessarily focused on the needs of people of color within the movement. There are a lot of issues that they are faced with that...a Caucasian person with a disability might not recognize.

One disability organization in California that has had success in incorporating the needs of minority individuals with disabilities and their families is Community Resources for Independence, the Sonoma County ILC in Santa Rosa, California. In 1995 and 1996, CRI opened two branch offices in Mendocino and Lake counties in order to improve education, outreach, and service delivery to underserved populations in these surrounding areas, particularly Native Americans. According to Randy Feliz, vice chair of the Hopland Band of Pomo Indians, there are approximately 20 federally recognized reservations or rancherias in Mendocino, Lake, and Sonoma counties, with an estimated population of 6,000, representing about 26 percent of the total population for these counties. The issues of poverty, isolation, alcoholism, and poor health care are so widespread in this area that those with disabilities find that their specific needs are very low priorities.[45, 46]

In order to respond to the needs of Native Americans with disabilities, CRI developed an outreach plan based on cultural respect, mutual education, and a clear understanding that "the Native American community must be the driving force" behind "any project or activity...undertaken."[47] In 1995, CRI received a grant from the California Department of Rehabilitation to launch the Native American Community Organizing Project (NACOP), a fundamental part of CRI's outreach program. CRI hired a Native American Community Liaison Coordinator to assist in its outreach efforts to the various tribal communities in the area. These outreach efforts included letters, phone contacts, and active involvement in the community through participation in several Tribal Council meetings, community social gatherings, and Indian Health Center meetings.[48]

In 1996, CRI's outreach efforts continued with the organization of a meeting in Ukiah to begin planning to apply for a Section 130 grant to bring Native American vocational rehabilitation services to the Sonoma, Mendocino, and Lake counties. Soon after this meeting, CRI received a grant from the California PAS Project. With this grant and additional funding from several Tribal governments and casinos, CRI and the NACOP director proceeded to research, organize, and develop a resource manual entitled *Accessing Native Americans with Disabilities*. In November 1996, this manual was distributed to several agencies within the state, including SILC, California ILCs, the Native American Reservation/Rancherias in California, and the California Department of Rehabilitation. Shortly before the distribution of this resource manual, CRI conducted targeted recruitment of Native Americans with disabilities in the surrounding area to be representatives on the Native American Disability Advisory Council, which was charged with overseeing and monitoring the NACOP's progress toward developed goals and objectives. In April 1998, CRI and the members of the Native American Disability Advisory Council submitted an application for a Native American Independent Living Center grant.[49] This would have been the first ILC of its kind in California, but CRI was subsequently informed that neither this grant nor the Section 130 Project grant had been funded. The NACOP funding, furthermore, was not renewed in 1998.

In spite of these setbacks, CRI has continued its commitment to meeting the unique needs of Native Americans with disabilities in its service area. CRI has accomplished this goal by maintaining a presence within the tribal communities, thereby establishing a sense of trust within those communities; providing education for tribal members on disability issues; hiring Native Americans with disabilities to provide training for CRI staff on Native-American cultural issues; and continuing outreach efforts by using local newspapers and other minority media that target the Native American community and by distributing brochures and flyers in places frequented by Native Americans.[50]

As CRI's example illustrates, increasing awareness among minority individuals with disabilities and their families requires a long-term commitment, a visible presence in minority communities, and the development of a culturally appropriate outreach plan that has been established in collaboration with minority community groups. As witnesses at the 1998 NCD hearing in San Francisco indicated, an outreach plan must demonstrate a fundamental understanding of the cultural differences between minority and majority cultures. The strengths of minority cultures should be emphasized, including the role of the family and the importance of interdependence. The reliance in minority cultures on support systems internal to their ethnic communities should also be recognized and incorporated into all outreach efforts. Minority individuals with disabilities must be empowered as agents of change, who will work together toward altering their social status within their cultural communities. This element should also be incorporated through the use of minority media, the development of partnerships with community groups, and targeted distribution of information in places frequented by minorities.

## Recommendations

- Congress should amend the definition of "minority entities" under Section 21 of the Rehabilitation Act to once again include "community-based minority organizations."
- Congress should ask GAO to investigate the cultural and linguistic appropriateness of public information activities related to ADA, IDEA, the Fair Housing Act, and other federal civil rights disabilities laws.
- The Departments of Education, Health and Human Services, Labor, and Transportation, as well as the SBA should require their grantees and field offices to develop a culturally appropriate outreach plan that takes into account the fundamental differences between majority, minority and sovereign tribal cultures.
- The National Institute on Disability and Rehabilitation Research should require its research and training centers with emphasis on minority populations to develop and test guides describing the services provided by independent living centers that use appropriate cultural and linguistic terminology for diverse populations. Once these guides are produced, RSA should require CILS and SILCs to use the guidelines to improve their outreach and service delivery to diverse populations.
- Federal agencies funding outreach efforts should encourage initiatives directed not only toward diverse individuals with disabilities, but also toward their families and community organizations.
- Federal agencies conducting or funding outreach should emphasize that successful outreach requires an awareness of the perception of disability and related concepts like independent living that exists within a particular cultural community.

Section 21 of the 1992 amendments to the Rehabilitation Act directed the commissioner of the Rehabilitation Services Administration to develop a "plan to provide outreach services" to "minority entities" in order to "enhance their capacity and increase their participation in competitions for available financial assistance." Under the 1992 amendments, "minority entities" were defined as (1) Historically Black Colleges and Universities, Hispanic-serving institutions of higher education, and other institutions of higher education whose minority student enrollment is at least 50 percent; (2) nonprofit and for-profit agencies at least 51 percent owned or controlled by one or more minority individuals; and (3) underrepresented populations.

In response to this congressional mandate, RSA launched the Capacity Building Project in 1996 with the awarding of 17 grants to various educational institutions and nonprofit service agencies for the provision of outreach services to minority entities.[51] San Diego State University (SDSU) was among the 12 educational institutions that received RSA capacity building grants. According to Mari Guillermo, the capacity building project coordinator at SDSU, the SDSU project has been particularly successful in its outreach efforts to community-based minority organizations. In its first two years, more than 15 minority owned/controlled businesses received focused technical assistance from the SDSU project, and a participatory capacity building consortium was formed to promote collaboration and networking between community-based minority organizations that serve individuals with disabilities.[52]

Despite such gains, in the 1998 amendments to the Rehabilitation Act, community-based minority organizations were deleted from the definition of "minority entities" under Section 21. The new definition describes "minority entities" as institutions of higher education, which include American Indian Tribal colleges or universities, Historically Black colleges and universities, Hispanic-serving institutions, and other institutions of higher education whose minority enrollment is at least 50 percent.[53]

When questioned about this omission, an official of RSA's Capacity Building Project said he was "not sure why community-based minority organizations were left out of the amended definition of 'minority entities.'" "Although the 1998 amendments broadened what can be done," he said, "they also narrowed the target population…and this will have a direct impact on who we can reach." Another official for RSA's capacity building effort said the deletion of community-based minority organizations "will have a negative impact" on the overall goals of the project because these organizations play "an essential educational role in minority communities." An internal e-mail message circulated among RSA Capacity Building Project directors and minority community-based organization representatives further states:

> This deletion concerns us greatly because it affects the mission of our capacity building efforts, and more importantly it disregards the important role CBMOs (community-based minority organizatons) play in the lives of minority individuals with disabilities and their families from different cultures....Traditionally, [these] grassroots agencies have been the greatest source of support for individuals with disabilities and their families since the traditional service systems do not always reach [minority] communities.[54]

Given the essential service and outreach link that community-based minority organizations provide to minority individuals with disabilities, NCD recommends that steps be taken to address this setback. The issue should either be addressed in the rulemaking process or through an amendment to the Rehabilitation Act that includes community-based minority organizations in the definition of "minority entities" under Section 21.

All publicly funded programs serving individuals with disabilities should be required to develop a culturally appropriate outreach plan that includes outreach goals and objectives, and mechanisms for evaluation of outcomes. This plan should also take into account some of the fundamental differences between majority and minority cultures. For example, the independent living philosophy should be translated and presented in a culturally appropriate manner.

In order to promote meaningful inclusion of minority individuals with disabilities and their families in the disability community, concepts that are fundamental to the independent living movement, such as "individual empowerment," "self-sufficiency," "independent living," "control over one's life," and "minimal reliance on others," need to be translated and presented in a culturally appropriate manner. The role of interdependence, furthermore, should be considered as an equally viable alternative to independence in the current philosophy, goals, and practices of the movement.

Given the reliance in minority cultures on support systems internal to their ethnic communities, all outreach efforts should be directed toward these internal social structures, which include the family, religious organizations, recreational facilities, community groups, and other social institutions important in the lives of minority group members.

In order to effectively reach minority individuals with disabilities, all disability service agencies must be aware of the perceptions of disability that exist within certain cultural communities, and the ways in which these perceptions can influence the willingness of minority individuals with disabilities to use services provided by an agency outside of the family and/or cultural community.

### b) Language and Communication Barriers

As Kazue Lowenstein noted in her testimony, another important aspect of outreach and culturally competent service delivery that is routinely overlooked is "the language issue." For individuals who speak limited or no English, language barriers in particular, such as lack of bilingual service providers, interpreters, and language-appropriate materials, are a major obstacle to getting the resources they need. Xie Yu Ying had difficulty in all of these areas when she attempted to apply for Social Security benefits:

> I went to the Social Security bureau, but they all spoke English. I didn't understand any English. I found it was very difficult.... I obtained a form, but it was printed in English. I had to find someone to help me fill it out. I took it back two to three months later. I had more trouble when I handed it in because I didn't know any English and no one around could help me. I went there at 9 a.m. and waited till late. I saw someone Chinese coming this way, so I asked them what else I needed to provide. I spent a few more hours and didn't get back until 4 p.m. So I would like to request the government to have bilingual workers there to help us.

As Xie Yu Ying noted in her testimony, one of the main barriers to service delivery for limited- or non-English speaking individuals with disabilities and their families is the absence of service personnel who are bilingual. Laura Echegaray, ILRC Latino community disability educator, also noted the prevalent lack of bilingual service providers. "It is rare to find service providers who speak or understand Spanish," she said. "This limits access to information about rights, benefits, employment programs, and other opportunities." Manuel Vasquez, director of Mission Mental Health Services in San Francisco, concurred with this sentiment in his testimony. "One of the major difficulties experienced by disabled Latinos," he said, "is the lack of cultural access to many support services because of a lack of language capacity among many service providers."

The need for bilingual service providers is particularly apparent in the area of special education. According to the testimony of Maggie Dee, president of California Democrats with Disabilities, "parents" of children with disabilities "who are non-English speaking" have tremendous difficulty "finding appropriate agencies to assist in language-appropriate help" when "trying to enroll their child or children in special education for the first time." Anthony Rienzi, a psychiatrist at Alta Bates Medical Center, also noted that "youth with disabilities and their parents" who "only speak Spanish or an Asian language" have "problems...when trying to obtain [related] services." Gui Lan Lam, a parent who had difficulty obtaining services for her daughter, Mimi, testified of problems that arose as a result of "the language barriers" when she was applying for assistance for her daughter. Donna Reid, a mother of two children with disabilities, said that when parents who "have language barriers" are unfairly denied related services, they are "often afraid to speak up because communication alone prevents them from being able to adequately question the process."

Even if parents are able to enroll their children in special education and obtain related services for them, they still face significant language barriers in everyday communication with school personnel. Ramona Chacon, a parent of a child with a disability, said one the greatest "challenges monolingual parents have with the school district is not being able to communicate with the personnel." As Nancy Lim-Yee pointed out, "While interpreters are provided for "official" meetings, like IEPs, they are seldom available for informal, everyday communication." This issue is further complicated for minority parents of children who are deaf or hard of hearing. Not only do they need access to a spoken language interpreter, they also need access to an American Sign Language interpreter. Cheryl Wu and Nancy Grant, who work for the Hearing Society for the Bay Area, discussed this issue in their written report:

> When parents speak one language, services are offered in English, and their child uses American sign language, interpreters can be helpful; however, three-language communication takes a lot of time, patience, and skilled management.... Evaluating interpreter skills can be difficult; finding and paying fairly for an interpreter with the language(s) you need, and having them available when you need them can be difficult.

Several other participants at the hearing also noted the lack of access to interpreting services. In his testimony, Liu Fu Hai said he has had "problems finding an interpreter." Even though Yu Su Xiao had access to an interpreter when he applied for workers' compensation, the interpreter "didn't help," he said, "but instead, called up the guard to drive me out the door." Ming Quan Chang, a family and child advocate at Cameron House, noted that one of her clients "had to wait at least four hours at a hospital to get an interpreter." Once the interpreter was provided, her client still had "difficulty understanding." Even though the interpreter "translated exactly what the doctor said," Ming Quan Chang pointed out that "there's still a cultural gap among Chinese, Vietnamese, and American culture." Cheryl Wu and Nancy Grant agreed with this observation in their written report:

> Interpreters are a valuable resource in many situations; however, they do not solve the problem of communication either between deaf and hearing or between spoken languages.... Too often interpreting/translation addresses only "words," and doesn't take into account the need for translation of cultural concepts, behaviors and body language, expectations about relationships, and jargon (medical terms, educational acronyms). Printed as well as spoken communication needs to address these issues.

Laura Echegaray concurred and further suggested that agencies should "try to avoid literal translations as much as possible" because "there are many terms that turn very complicated or lose sense when translated." "It is better to produce culturally appropriate adaptations," she said, "based on the available English information." In her testimony, Rocio deMateo-Smith, executive director of California Area Board 5 on Developmental Disabilities, provided an example of the complications that can happen when interpreters "only address words":

> I just had to help out with a situation where a Farsi-speaking family was not receiving the services they needed. The main block was the Farsi-speaking [interpreter], who was the only road into that family's information. Sometimes when you do not have the right information giver, you are at that much of a disadvantage.

As Cheryl Wu and Nancy Grant noted, communication problems can also occur on the basis of cultural differences in body language and communication styles. Nancy Lim-Yee says that the "'body language' of nodding and smiling signifies agreement in American culture," but in "many Asian cultures it is a way of keeping harmony, saving face, and does not necessarily reflect agreement regarding the topic being discussed." Paul Leung has noted that "Communication styles have contributed to misunderstanding between Asian Pacific Americans and others. Strong emotional confrontations are not generally as well accepted with Asian cultures and the desire is to keep things on an even keel."[55] In her testimony, Beverlyn Lee observed that her communication style has also been misunderstood:

> As an African American woman, I come from a proud tradition of oral history. My communication style is consistent with my cultural and ethnic background....Oftentimes my communication has been misinterpreted as hostile or aggressive.

Other language and communication barriers discussed at the 1998 NCD hearing include direct telephone access, limited funding for translation and interpretation services, and the absence of translated materials in alternative formats. Cheryl Wu and Nancy Grant reported that "Phone trees and English only answering systems are a serious barrier to access." Laura Echegaray emphasized the tremendous need for "direct telephone access to Spanish-speaking service providers."

In her testimony, Shiva Schulz, director of employment support services at the Association for Retarded Citizens in San Francisco, said that ARC recognized "the importance of readily available funding for ESL services, and ESL services that are appropriate for individuals with disabilities, but we have not found suitable options in the community or funding for us to offer it at our site." Nancy Lim-Yee also felt that "more funds" should be made "available to translate important materials and information into various Asian/Pacific Islander languages, and to put information on videotape for families who may not be literate." Lourdes Mugas-Talan of the Hawaii Centers for Independent Living agreed. To address the "language barriers," she said, there should be funding "to make the printed materials available for people in their own languages...and to share information by video." Kathy Abrahamson and Kathy Knox, who work for the Rose Resnick Lighthouse for the Blind in San Francisco, noted in their written report that "Nonprofit agencies cannot generally afford to produce information in both alternative format and more than one language; governmental agencies and services, according to several of our respondents, make no attempt to do either."

Following the 1998 NCD hearing, Ms. Abrahamson and Ms. Knox conducted a series of interviews and found that another language and communication barrier for people from diverse cultural communities who are blind or visually impaired is the almost complete absence of language-appropriate materials available in alternative formats, particularly from governmental agencies and services. "Forms that might be available in Spanish or Chinese," they wrote, "are also only available in very small print."

## Recommendations

Based on the testimony presented at the 1998 NCD hearing, therefore, it is clear that minority individuals with disabilities and their families still encounter multiple language and communication barriers in signed, written, and spoken language. Among these barriers are the lack of bilingual service providers, interpreting services, and language appropriate materials; differences in body language and communication styles; and English-only phone services, limited funding for translation and interpretation services, and the absence of translated materials in alternative formats. To address these language and communication barriers, NCD makes the following recommendations.

- The Departments of Education, HHS, HUD, and DOT and the SBA should require that their field offices and grantees conduct targeted recruitments and hiring of diverse individuals who are bilingual and bicultural, especially diverse individuals with disabilities.
- The Office of Special Education and Rehabilitative Services should issue a policy memorandum mandating targeted recruitment and hiring of bilingual special education staff at all levels.
- Federally funded disability programs should conduct targeted recruitment and hiring of minority individuals who are bilingual and bicultural.

In order to address the lack of language capacity among many disability service providers, NCD recommends that all disability service agencies, particularly those in areas with a high minority concentration, conduct targeted recruitment and hiring of minority individuals who are bilingual and bicultural. Minority group members with disabilities and their families who are limited- or non-English speaking need to have direct and immediate access to qualified, bilingual disability service staff who are sensitive to their cultural needs and knowledgeable about resources available in their cultural community.

- RSA should include language interpreter information and referral as a core service at all centers for independent living servicing significant populations of non-English-speaking people within their service area.
- RSA should require all Centers for Independent Living (CIL) with significant non-English speaking populations in their service area to develop language/communication action plans that include:
    - Establishing contacts within minority community agencies who can assist in facilitating communication with ethnically diverse populations.
    - Developing a language interpreter referral database that is available in multiple languages and alternative formats, including the World Wide Web.

  - Sending all existing or new translated materials to the SCLC for widespread distribution to other Centers for Independent Living and related agencies/organizations in the state.
  - Establishing sign language and other language and other interpreter/translator training programs that provide instruction on translation of cultural concepts, behaviors and body language, expectations about relationships, and other technical disability-related terms (e.g., medical terms and educational and legal acronyms).
  - Providing language-dedicated telephone lines in Spanish and other languages with information in bilingual formats on Web pages.
- The Departments of Education, Health and Human Services, Housing and Urban Development, Labor, and Transportation and the Small Business Administration should make available adequate funding to all field offices and grantees for translation and interpretation services.
- Congress should ask GAO to investigate the quality of service delivery for diverse individuals with disabilities and their families in terms of language and cultural competence.

Although several disability service agencies have recognized the importance of readily available interpreter and translation services, few funding sources are available to provide these services. To address this situation, several witnesses at the hearing suggested that more funding should be provided for interpretation and translation of important agency materials into both bilingual and alternative formats. Funding was also requested for the specific purpose of translating agency materials and placing them on videotape for minority individuals and their families who may be illiterate or have a significant learning disability.

## C. BARRIERS TO CITIZENSHIP

### 1. Overview

This chapter discusses the history of U.S. immigration policy concerning people with disabilities. Although overt official bias has largely been eradicated, as this report described earlier, systemic obstacles remain to fair and efficient consideration of citizenship applicants with disabilities. These include reasonable accommodations in the areas of testing, fingerprinting, and the oath of allegiance.

The National Council on Disability recommends that the U.S. Department of Justice conduct a thorough investigation of INS policies and practices concerning people with disabilities. The Immigration and Naturalization Service should institute clearer accommodation policies and train staff to process such requests. NCD also recommends that Congress authorize the Attorney General to waive the oath requirement as appropriate.

### 2. Analysis

"The disability movement has been viewed as a White, middle-class movement, and we're demonstrating the need to enforce the civil rights and legal rights among immigrants and people of color," says Stephen Rosenbaum, a senior litigation attorney for the Disability Rights Education and Defense Fund (DREDF) in Berkeley. "We are bringing together immigrant and disability communities, making each aware of the other's concerns because some are doubly marginalized or disenfranchised. But then, what greater enfranchisement is there than obtaining citizenship for this group?"[56]

According to San Francisco immigration lawyer Eugene C. Wong, "Congress has called naturalization the most valued governmental benefit of this land." Pun Fong Chi, a Chinese national recovering from colon cancer, expressed this sentiment in her testimony at the 1998 NCD hearing in San Francisco when she presented the members of NCD with one solitary request:

> I have a wish, that is to become an American citizen. I went to study naturalization at Xin Qiao Service Center, a nonprofit organization. The teacher is

> very good. I study very hard. I now hope the government will give us mental support and encouragement so that it won't be too hard to become citizens.

Unfortunately for Pun Fong Chi, and for the thousands of immigrants with disabilities like her, the United States has a long and well-documented history of discouraging and actively restricting the immigration and citizenship of people with disabilities, especially those from certain racial and ethnic communities. At the end of the 19th century, Congress passed several acts that provided for the physical examination of immigrants, and excluded from the United States those who were found to be "convicts, polygamists, prostitutes, persons suffering from loathsome or contagious diseases, and persons liable to become public charges."[57] One of these acts, the Chinese Exclusion Act of 1882, specifically barred not only the admission of Chinese but also the admission of "lunatics and idiots." In 1903, Congress took this one step further to bar the admission of people with epilepsy.[58]

These immigration restrictions for people with disabilities continued throughout the 20th century. They increased in scope and intensity after 1907, when the United States admitted the highest number of immigrants in its history.[59] There have been several calls for immigration restrictions explicitly linked to the exclusion of people with disabilities. In 1917, E. J. Emerick, president of the American Association for the Study of the Feeble-Minded, warned against the free admission of immigrants, an alarming number of whom he said were "mentally deficient."[60] Heeding this warning, Congress considered legislation in 1917 to bar "persons of constitutional psychopathic inferiority."[61] In that same year, Henry H. Goddard began administering Stanford-Binet intelligence tests to immigrants on Ellis Island. According to Goddard's 1913 report to the American Association for the Study of the Feeble-Minded, the administration of these tests to immigrants was useful because "the Binet scale could detect the mentally defective more quickly and more accurately than methods being used by physicians."[62] It was during this prewar period that well-known eugenist Madison Grant issued his own warning against the immigration of people with disabilities from diverse cultural communities in his best-selling book, *The Passing of the Great Race*. Unless the country excluded inferior racial and ethnic groups, Grant warned, the superior Nordic strain would be overtaken by "the weak, the broken, and the mentally crippled."[63] This sentiment was expressed even as late as 1945 when E. Arthur Whitney argued that "a thorough screening by the immigration authorities would eliminate not only the mental defectives but those of mental defective or psychopathic stock who will be clamoring for admission now that World War II is at an end."[64] It was not until 1965 that Congress finally removed the majority of the immigration restrictions outlined above for people with disabilities.[65] It is clear, therefore, that over the past century the United States has done little to fulfill the request of Pun Fong Chi to support and encourage the immigration and citizenship of people with disabilities from diverse cultural communities.

In spite of the legislative reversal more than 30 years ago, the pattern of discouraging and actively restricting the immigration and citizenship of people with disabilities continued into the end of the 1990s through a more subtle and indirect exclusionary practice of denying immigrants with disabilities their right to reasonable accommodations in the naturalization process. This issue came to a head two years ago, in the wake of congressional welfare reform efforts, when immigrants with disabilities throughout the United States suddenly faced the possibility of losing their medical and Social Security benefits if they did not become U.S. citizens.

On August 22, 1996, President Clinton "ended welfare as we know it" by signing into law the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, more commonly known as the welfare reform law. This piece of legislation dramatically altered the welfare system and restricted access by legal and illegal immigrants to a wide range of public benefits, including Supplemental Security Income and food stamps. In addition, it gave states the discretion to determine whether legal immigrants would continue to be eligible for federal cash assistance under several federal programs, one of which was Medicaid.[66] In California, SSI/SSP (State Supplementary Program) recipients are categorically eligible to receive Medicaid (known as Medi-Cal in California) and In-Home Supportive Services (IHSS). Although the IHSS program was not specifically mentioned in the welfare reform law, in California IHSS benefits are limited to persons who are eligible for SSI/SSP.[67] As a result, upon enactment of the federal law, a majority of the noncitizens in California were not only ineligible for SSI/SSP, as of January 1, 1997, they were also ineligible for Medi-Cal and IHSS.

According to the state legislative analyst's office, as of July 1996 approximately 330,000 legal noncitizens were receiving SSI/SSP in California, representing about 40 percent of all the noncitizens in the United States receiving SSI.[68] The California Department of Social Services estimated that 243,700 of those recipients were unlikely to meet any of the exception criteria outlined in the federal law, which included refugees and asylees in their first five years of residence, veterans and their dependents, and lawful permanent residents who have worked in the United States for approximately 10 years. As a result, almost 74 percent of the legal noncitizens in California stood to lose their SSI benefits, and other related benefits (Medi-Cal/IHSS), if they had failed to attain U.S. citizenship before enactment of the federal welfare reform law.

On June 23, 1997, NCD released a position paper on the "Impact of the Welfare Reform Legislation on Legal Immigrants with Disabilities," which expressed "serious concern...at the economic, physical, and emotional injury that the 1996 welfare reform legislation will inflict...on legal immigrants with disabilities."[69] Among those hardest hit by the law, NCD predicted, would be "the permanently disabled who are dependent on SSI, food stamps, and Medicaid for their support and medical care":

> The denial of benefits will require immigrants with disabilities to rely even more heavily on others, stretching the resources of their families and sponsors (if they have family and sponsors) who, though gainfully employed, in many cases do not have sufficient resources to support them. Without SSI payments, food stamps, and Medicaid, state and local governments and private charities will become the prime source of assistance to legal immigrants with severe disabilities, and there is reason to fear that competing interests and agendas and thinning budgets will prevent these groups from adequately filling the gap.

To address this situation, NCD recommended, among other things, that "naturalization be afforded to all qualifying individuals with disabilities, regardless of the severity of the disability." President Clinton responded to the concern by issuing a directive to all Cabinet agencies to provide support for the naturalization of immigrants who qualified and desired to become U.S. citizens.[70] In spite of this directive, the "support" that President Clinton called for was not forthcoming insofar as immigrants with disabilities were concerned, particularly from the agency responsible for the processing of citizenship applications, the Immigration and Naturalization Service. As NCD noted in its 1997 position paper, the welfare reform act "has served to highlight a fundamental problem with the immigration laws of this country," that is, the inability of individuals with severe disabilities to become U.S. citizens. According to the written testimony of Stephen Rosenbaum, a senior litigation attorney for DREDF in Berkeley:

> Although the Justice Department's regulations for enforcement of nondiscrimination on the basis of disability in federally conducted programs became effective in 1984, the INS has never taken Section 504 seriously and the agency has demonstrated their unfamiliarity with and reluctance to carry out its responsibilities under these regulations.

It was only after DREDF filed a nationwide class action lawsuit against INS in 1996 that INS finally adopted regulations implementing federal "disability waivers" as required by the Immigration and Nationality Technical Corrections Act of 1994, which had been passed by Congress more than two years earlier. This statute exempts citizenship applicants with "physical and developmental disabilities" or "mental impairments" from the citizenship requirements of English literacy and knowledge of U.S. civics.[71] Despite these regulations, as NCD noted in 1997, "given the backlog of citizenship applicants, there are no assurances that newly exempted immigrants will be able to take advantage of the new rules in time to prevent their benefits from being cut off."[72]

In addition to prolonging the adoption of regulations implementing federal "disability waivers," INS has continued to erect other barriers to citizenship for immigrants with disabilities, particularly for those with developmental, psychiatric, and significant physical disabilities. In oral and written statements for the 1998 NCD hearing in San Francisco, Stephen Rosenbaum testified on behalf of 10 citizenship applicants with disabilities who alleged that they were currently being discriminated against by INS through the denial of reasonable accommodations and policy modifications in three particular stages of the naturalization process: the naturalization interview, fingerprinting, and the execution of a "meaningful" oath of allegiance.

### a) Naturalization interview

On July 2, 1998, DREDF attorney Jesiros D. Bautista and the law offices of Eugene Chi-Ching Wong in San Francisco filed a joint complaint with the U.S. Department of Justice alleging that the San Francisco District INS Office had violated Section 504 by failing to accommodate six citizenship applicants with significant disabilities who were unable to leave their homes.[73] Among the applicants was a woman residing in San Francisco who was unable to leave her bed following a series of surgeries over the past decade to correct a joint and pelvic problem. She was able to attend her last doctor's appointment only by remaining completely supine in an ambulance. Similar transportation to the San Francisco INS office for the naturalization interview and oath-taking ceremony would cost this woman approximately $1,150 for each trip, the complaint said, and would entail a great deal of physical danger and pain. As a result, when she filed her naturalization application, her attorney requested a telephone or in-home interview as a reasonable accommodation. On February 4, 1998, however, she received a telephone message from INS informing her, with no further explanation, that her request for an accommodation had been denied.

Another applicant, an 82-year-old Thai national, was on a constant feeding tube as a result of a stroke and could communicate only by blinking. In August of 1997, her attending physician wrote a letter to INS explaining that this woman could not leave her bed, and that to do so would endanger her health. The physician and the woman's daughters requested "other arrangements" in lieu of an office interview. The woman's attorney repeated the request for an in-home interview less than a year later. In spite of these repeated requests for accommodation, an INS representative phoned the attorney to say that INS lacked the resources to conduct in-home interviews.

Two other complainants were an 88-year-old Chinese national and a 69-year-old Chinese national, both of whom are unable to leave their homes because of their significant disabilities. Each of these applicants requested an in-home interview as a reasonable accommodation from INS, but neither of these applicants had received a response by the time the complaint was filed.

The remaining applicants were a 93-year-old Argentinean national and a 93-year-old Iranian national. The first woman was supported by a feeding tube and remained permanently in bed with multiple disabilities, including dementia, blindness, and Parkinson's disease. The other woman was fed intravenously and was unable to leave her bed because of permanent and progressive Alzheimer's disease. Each of these women requested an in-home interview as a reasonable accommodation from INS. INS ignored their requests, and they were sent a notice to come to the INS office in San Francisco for an on-site interview.

As a federal agency, INS is subject to the provisions of Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination against people with disabilities by any "program or activity receiving federal financial assistance."[74] Under the regulations for Section 504, the naturalization process is considered a "federally conducted program or activity," and INS is required "to make reasonable accommodations and modifications" for "qualified individuals with a disability" who are participating in the naturalization process.[75] Clearly, the complaint said, all of the applicants mentioned above were "qualified individuals with a disability." They had a "physical or mental impairment which substantially limits one or more" of their "major life activities," and they met "the essential eligibility requirements" to become a U.S. citizen.[76] Despite this, they were all apparently denied their legal right to a reasonable accommodation in the naturalization process. Their requests for a telephone or in-home interview were either denied or left unanswered, or they were told that INS lacked the resources to conduct in-home interviews.

A public affairs director for the San Francisco District INS office was quoted in both the *San Francisco Chronicle* and *Asian Week* as saying that INS has "always tried to provide for the disabled."[77, 78] "Every single day," she said, "we make accommodations for the disabled that are able to come to the office for interviews by arranging for special hours or providing for special accommodations that will ensure their comfort and expedite their naturalization." Whether or not INS accommodates applicants with disabilities who are able to go to the office, however, is not the issue in dispute in this particular complaint. When questioned by a reporter about the specific charge in the DREDF complaint that INS fails to accommodate applicants with significant disabilities who are not able to leave their home, the INS official categorically denied this charge and noted that in June 1998 a Santa Rosa resident was naturalized at her bedside. As Janet Dang of *Asian Week* pointed out, however, even though the Santa Rosa resident was naturalized at her bedside, the preliminary interviews for this applicant took place at the INS office.[79]

According to Stephen Rosenbaum's written testimony, in a March 12, 1997, internal INS policy memorandum, it recognized that "making acceptable accommodations or modifications to the entire naturalization process is [INS's] mandate.under the Rehabilitation Act of 1973."[80] "Similarly," Rosenbaum argued, "in the preamble to the final regulations implementing the disability waiver it states that 'it is current Service policy to conduct off-site testing, interviews, and, where authorized, off-site swearing-in ceremonies in appropriate situations.' "[81] The six cases mentioned in the complaint and described above are all arguably "appropriate situations" for an off-site interview given that an on-site interview in all of these cases would either severely compromise the applicant's health or be prohibitively expensive. According to the testimony of Stephen Rosenbaum, however, these cases are not unusual. When it comes to accommodating citizenship applicants with disabilities, these problems exist in every area of the naturalization process, including the fingerprinting requirements.

In response to criticism that there is no standard method for applicants with disabilities to request accommodations in the naturalization process, in its 1999 revisions of the naturalization application, form N-400, INS included a question about needed accommodations. INS hopes that by standardizing the accommodations request procedure, and getting more advance notice of the need for accommodations, it will be better able to respond to the needs of applicants with disabilities.

### b) Fingerprinting requirements

In April of 1997, Tal Klement, a law student at Yale University, filed his United States citizenship application with the INS district office in San Francisco. Although INS publishes that its policy is to "strive to maintain an average time of approximately six months for the entire naturalization process,"[82] in June of 1998, Klement was still no closer to becoming a citizen than when he filed his application 15 months before.[83] On September 22, 1997, Mr. Klement received a form letter from INS stating that his fingerprints were "unclassifiable," and therefore he had to submit new ones.[84] Klement was born with shortened arms, three fingers on his right hand and two on his left, which made his first set of prints "unclassifiable" because it was not a full set of 10 fingers. At the time, INS required that all citizenship applicants submit their fingerprints to establish the applicant's identity for criminal background checks.[85] INS policy has been that every applicant whose prints are rejected must return for a second printing before INS will ask the FBI to run a name check.[86] However, in response to difficulties of some applicants in providing even a single legible fingerprint, in the spring of 1999 INS announced a waiver procedure that exempts this group of applicants from having to return to be printed again, based on a waiver given by the INS employee in charge of the fingerprinting operation. Instead, such applicants can immediately satisfy the background check requirement by submitting local police clearance.

Equipped with medical certification of his disability and police verification of his clean record, Mr. Klement returned to submit a new set of prints, only to receive another form letter from INS advising him that his fingerprint card was rejected because the FBI could not "classify" or "read" his prints.[87] No further explanation was given, and there was no mention of his disability anywhere in the letter. Despite three letters from his congressional representative, and repeated requests for a modification of INS fingerprint policy, over the next few months INS continued to require that Mr. Klement submit additional prints. It was only after DREDF intervened and filed a Section 504 complaint on behalf of Mr. Klement that INS finally agreed to accept his police clearances and expedite his citizenship application.

When questioned about Mr. Klement's situation, an INS spokesperson was quoted in *The Washington Post* as saying, "The whole system is designed to rely on the fact that 99.999 percent of the world has fingerprints that work. Anything that falls outside that is much harder to deal with."[88] From Mr. Klement's viewpoint, it was not his fingerprints that were the problem, but rather the intransigence of an agency that refused to modify its policies in order to accommodate citizenship applicants with disabilities.

Ravinder K of India agreed with this sentiment, as she too is one of the .001 percent of the world whose fingerprints do not seem to "work." Ravinder K has cerebral palsy, and as a result she is unable to open her right hand wide enough to make a readable print. Like Mr. Klement, Ms. K submitted two sets of fingerprints, both of which were rejected by INS. According to the Section 504 complaint filed by DREDF on behalf of Mr. Klement and Ms. K, "For months, Ms. K has been requesting an accommodation or modification of INS policy to allow her to undergo an alternative security clearance or criminal background check through some means that does not involve taking prints."[89] At the time of the NCD hearing in San Francisco, however, Ms. K still had received no response from INS acknowledging her accommodation requests. As in Mr. Klement's situation, INS continued to demand that she submit additional prints. It was apparent that Ms. K would encounter the same difficulties in producing a readable print no matter how many times she was fingerprinted. In spite of this, INS ignored her request for a reasonable accommodation and policy modification, thereby delaying the processing of her citizenship application.

Until the new policy took effect, INS's policy was that all applicants must receive two ratings of their prints as "unclassifiable" by the FBI before they were allowed to submit clearance from local police jurisdictions. However, two issues have caused many applicants to have to submit prints more than two times. First, INS's fingerprint program was modified drastically in the fall of 1997, when Congress mandated that INS begin in-house fingerprinting programs. Because many prints taken under the previous program were unclassifiable, many applicants who had submitted prints taken by non-INS entities were required to appear again to be fingerprinted at an INS location because INS could no longer accept prints by any other outside entity. Most of these transition difficulties should be resolved by now. In addition, INS only accepts the results of FBI fingerprints checks for 15 months; after that point the applicant must have another check completed. Unfortunately, an unprecedented number of naturalization applications have had to submit prints again, often multiple times, even if their first fingerprints were readable by the FBI.

It is to be hoped that the new INS waiver policy will eliminate these problems for applicants in the future.

### c) Oath of allegiance

To become United States citizens, all naturalization applicants must take an oath of allegiance, swearing to "support the Constitution and obey the laws of the United States." An applicant's success ultimately hinges on whether he or she is able to demonstrate an ability to take a meaningful oath of allegiance. To become citizens, applicants must convince INS that they are cognitively aware of the oath, their situations, and the actions they are taking."[90] These requirements prompt the following questions: What constitutes a "meaningful" oath of allegiance? What happens when applicants cannot demonstrate that they are "cognitively aware of the oath, their situations, and the actions they are taking" because they have a significant cognitive impairment, such as a significant developmental or psychiatric disability?

Unfortunately for Mr. W, a citizenship applicant with a significant developmental disability, the answer to the former question was never given, and the answer to the latter question was a denial of his naturalization application. On November 9, 1997, Mr. W received a letter from INS informing him that his application for naturalization had been denied because he "does not possess the capability of understanding the requirements and responsibilities of citizenship as stated in the oath of allegiance in any other language or through other communicative means."[91] This decision was primarily based on Mr. W's July 19, 1996, naturalization interview, during which the District Adjudications Officer asked Mr. W's father whether his son understood the oath of allegiance. According to correspondence between Stephen Rosenbaum and INS, Mr. W's father answered that he did not know if his son understood the oath, but he was confident that his son would understand it if his father were able to explain it to him.[92] This request for a policy modification of the INS oath requirement was denied, and Mr. W's naturalization application was turned down because he was unable to demonstrate his ability to take a "meaningful" oath of allegiance.

According to a Section 504 complaint filed by DREDF on behalf of another applicant with a developmental disability who was also found by INS to be "incapable" of understanding the oath of allegiance, INS's 1997 supplemental policy guidance for disability naturalization adjudications provides that "offices should be creative in constructing additional accommodations and modifications" and adjudication officers "cannot expect that interviews with many persons with disabilities will proceed or be conducted in the same way as applicants without disabilities."[93] Despite this policy, applicants with significant developmental disabilities are being held to the same standard set for applicants without disabilities as far as the oath of allegiance is concerned. They are required to demonstrate in an interview, with no accommodations or modifications, their capacity to understand and execute a "meaningful" oath of allegiance, even though the very nature of their disability may prevent them from doing so without some level of accommodation. Furthermore, as NCD noted in its 1997 position paper, this issue is complicated by the fact that "naturalization examiners are not trained to evaluate a disabled applicant's ability to comprehend what is taking place."[94]

The effect of denying applicants with disabilities their right to an accommodation or modification of the oath requirement is to systemically screen out applicants with developmental and psychiatric disabilities "solely by reason of [their] handicap," in violation of Section 504 of the Rehabilitation Act of 1973.

As Stephen Rosenbaum noted in his oral testimony before the members of NCD,

> Unfortunately, for the people who get through the tests of literacy and civics, and get through the interview process, at the end of it all if they don't know what the oath of allegiance is or what it means, they fail the test. For a lot of people with severe mental retardation, in particular, whose lives remain here with their families (they will not be leaving the country and are not a threat to national security), these people are denied citizenship at the end of the day and are essentially rendered "stateless."

For citizenship applicants with disabilities, INS has continued to enforce the requirements that all applicants have the "capacity to take a 'meaningful' oath of allegiance." Congress did not address the oath requirement when it enacted exceptions from the English and U.S. history and government tests for applicants with certain disabilities. As a result, INS officers are unable to make accommodations pertaining to the applicants' understanding of the oath.

However, INS has instructed its officers to make accommodations in the way they communicate with applicants with disabilities, such as relying on blinks as a signal for understanding, if that is the applicant's usual method of communication.

### Recommendations

Based on the testimony provided by Stephen Rosenbaum on behalf of the 10 citizenship applicants noted above, it is evident that the historical practice of discouraging and actively restricting the immigration and citizenship of people with disabilities still occurs on a regular basis. Although laws are no longer passed that specifically bar the immigration of people who have epilepsy and other disabilities, the pattern of discrimination against potential citizens with disabilities has continued through the denial of reasonable accommodations and policy modifications throughout the naturalization process.

In May of 1997, INS developed an "action plan" to address the systemic problems within the naturalization program, and to ensure that "naturalization quality procedures" were in place. Based on the evidence presented at the 1998 NCD hearing, it appears that INS district offices are receiving little policy guidance from INS headquarters on how to process reasonable accommodation requests from applicants with disabilities. Lacking definition and guidance, INS district offices have dealt with this situation by either placing these requests on hold until they receive some direction from Washington, or ignoring the requests and expecting applicants with disabilities to proceed through the naturalization process without accommodations. Either way, the result is delays in processing of their applications by as long as two to three years, or sometimes even indefinitely. During this period, applicants with disabilities and their families are in limbo. Their naturalization applications are neither granted nor denied. Thus they are precluded from filing any kind of appeal because the only formal grievance procedure available, according to Stephen Rosenbaum, is an appeal of a denial of naturalization, not a denial of accommodation. Based on the cases described in this report, it appears that there is no formal grievance procedure in place, either to appeal a denial of accommodation or to report a failure on the part of INS to reply to accommodation requests. If an ADA/504 Compliance Office exists, the applicants described in this report were not made aware of it. None of the applicants were given the opportunity to fill out an accommodation request form when they submitted their naturalization applications. In the absence of any kind of formal accommodation request procedure (apart from the disability waiver application), they simply wrote letters or called to request the accommodations and submitted their medical documentation separately. Every time they called INS to inquire about the status of their accommodation requests, however, their inquiries were left unacknowledged.

For these reasons, NCD recommends that the following actions be taken:

- Congress should ask GAO to conduct a study of INS compliance with disability access mandates under federal law, examining in part whether the changes put in place in the past year have resolved the long-standing problems identified in this report.

- INS should conduct training for field staff regarding the new procedures and policies outlined in its April 7, 1999, memorandum, and training should be completed by October 1, 1999.

- Congress should amend the Immigration and Nationality Act to provide for a disability waiver for the oath of allegiance requirement.

- INS should ensure timely processing of naturalization applications for applicants with disabilities.
- The Disability Rights sections of the Civil Rights Divisions of DOJ, NCD, and INS should work together to monitor implementation of INS's recent efforts to address long-standing problems with its naturalization process regarding access for applicants with disabilities and to address ongoing problems as they occur. To further this effort, the DOJ should institute a toll-free number, to a central location staffed with trained multilingual employees, where anyone encountering problems with accommodations during the naturalization process could raise those issues and the staff would track the nature of the problem and take steps to address both the individual and systemic issues identified. The toll-free number should be publicized in numerous languages in every INS office and published on all INS forms and materials.
- Individuals with significant developmental and psychiatric disabilities should not be prohibited from becoming citizens for the sole reason that they cannot demonstrate the capacity to take a "meaningful" oath of allegiance.[95]

In testimony at the 1998 NCD hearing, Eva Casas-Sarmiento, statewide outreach coordinator for Protection & Advocacy, Inc., asked the members of NCD to "make sure that people with disabilities who apply to become citizens are not placed at the bottom of the list. Right now, they are at the bottom of the list, and they're having to wait longer than other people to become citizens." In order to prevent the unnecessary delays described previously, NCD recommends that INS implement procedures to ensure that naturalization applications by people with disabilities are processed as efficiently as others.

## D. BARRIERS TO ACCURATE DEMOGRAPHIC DATA

### 1. Overview

This chapter discusses demographic data about minorities with disabilities and describes some problems in the statistics used to describe some cultural groups. Flawed data, though unintentionally circulated, may have an adverse effect especially on people with disabilities of Hispanic, Asian, or Pacific Islander descent.

The National Council on Disability recommends that the U.S. Bureau of the Census take steps to improve the tracking of data about minorities with disabilities. The approaching Census 2000 collection is a good place to start. It could include measures such as targeted recruitment of minority individuals with disabilities in the hiring process for temporary census workers.

Because mistaken statistics may have led to the underserving of Hispanics, Asians, and Pacific Islanders with disabilities, NCD recommends that federal disability programs conduct self-evaluations to ensure that this is not occurring. NCD also recommends that the National Institute on Disability and Rehabilitation Research (NIDRR) sponsor additional studies to improve demographic data about minority subcultures and intra-group differences.

### 2. Analysis

Throughout California's history, the population of the state has been characterized by its ethnic and cultural diversity. Even in the state's early history, more than 300 distinct tribes and language groups occupied the state.[96] Today, 150 years into statehood, California has a population that encompasses virtually every race, ethnic heritage, religion, and language group on the planet. The population of California is, indeed, among the most diverse and complex populations anywhere in the world, and no other developed region the size of California has sustained such rapid and tremendous population growth.[97] In 1997 alone, California's population grew by 582,000 people, to a total of 33,252,000.[98] While this population growth is remarkable in itself, what makes California's population increase especially remarkable is the nature and composition of that growth.

As recently as 1970, almost 80 percent of the state's residents were White.[99] Over the next three decades, however, California's population has undergone a tremendous shift in its racial and ethnic distribution. Between 1980 and 1990, Hispanic population changes accounted for 51.7 percent of the state's total population increase, and Asian/Pacific Islander population changes accounted for 24.1 percent of that increase.[100] Census data for 1990 showed that only 57 percent of the state's residents were White; 26 percent were Hispanic; 9 percent were Asians and Pacific Islanders; 7 percent were African Americans; and 1 percent were Native Americans.

Since 1990, Hispanic and Asian/Pacific Islander population changes have provided 91 percent of the state's total population increase.[101] The White population, as a proportion of the state's total population, declined to 53 percent in 1996. The Hispanic population rose to 29 percent, and the Asian/Pacific Islander population increased to 11 percent. The percentage of African American and Native American populations in California remained at 7 percent and 1 percent, respectively.[102]

Based on these trends, it is clear that around the turn of the century California will be the first of the 48 contiguous states with a majority population made up of racial and ethnic minorities. The political, economic, and social ramifications of this shift are major, particularly as they pertain to the prevalence of disability in the state among racial and ethnic minorities, and the corresponding inequality of service delivery that this rate of disability entails.

In the 1992 amendments to the Rehabilitation Act of 1973, Congress added a new section that called for the establishment of a Rehabilitation Cultural Diversity Initiative (RCDI) aimed at improving service delivery for minority individuals with disabilities in the state-federal vocational rehabilitation program. Among its primary justifications for adding Section 21 were Congress's agreement with findings that (1) "Ethnic and racial minorities tend to have disabling conditions at a disproportionately high rate" and (2) "Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational and rehabilitation process."[103] The finding that people from diverse cultural populations experience disabling conditions at a disproportionately higher rate is a well-established fact for certain racial and ethnic groups, particularly Native Americans and African Americans.[104-106] Several studies have found that Native Americans have the highest rate of disability of any racial or ethnic group in the United States, and African Americans have the second highest rate of disability and the highest rate of significant disability.[107] A study conducted by the University of California at San Francisco's Disability Statistics Rehabilitation Research and Training Center, based on data collected by the Census Bureau in 1991 and 1992 in its Survey of Income and Program Participation, found that the rate of disability in the U.S. population is 21.9 percent for Native Americans, followed closely by 20.0 percent for African Americans and 19.7 percent for Whites. For people of Hispanic origin, however, the study found that the disability rate (15.3%) was "significantly lower," and the rate for Asians and Pacific Islanders (9.9%) was "only half that for Whites and Blacks." Upon initial examination of these data, it appears that Hispanics and

Asians/Pacific Islanders do not fit the disability profile provided in the Congressional findings noted above; they have a lower rate of disability than any other racial and ethnic group in the United States, including Whites.

A closer examination of the data, however, raises sharp questions about making such generalizations and relying on the national census figures to determine the prevalence of disability within minority populations in the United States. This practice can lead to generalizations about Hispanic and Asian/Pacific Islander populations that mask the intra-ethnic diversity that exists within and among these groups. The testimony of Nancy Lim-Yee, a health worker at the Chinatown Child Development Center in San Francisco, supports this finding:

> The categories of "Asian," "Pacific Islander," and "Filipino" contain a great deal of cultural diversity, and differ as well in migration history prior to arrival in the United States, experience of wars, displacement, and other traumatic experiences. The Asian/Pacific Islanders include many subgroups and cultures and cannot be lumped together.

In fact, the "Asian and Pacific Islander" classification itself is made up of more than 40 distinct ethnic groups separated by differences in history, language, customs, values, and religion.[108] Lumping all of these groups into an aggregate category, the monolithic "Asian and Pacific Islander," masks significant differences, including differences related to immigration status and how long an individual has been in the United States, both of which can have a direct impact on the self-reported rate of disability in a census survey.

Within the past century, the majority of immigrants to the United States have come from Latin America and Asia. From 1990 to 1996 alone, 188,000 Hispanics and 452,000 Asians and Pacific Islanders immigrated to California.[109] Whether or not these immigrants would self-identify, and hence self-report in a census survey as having a disability, largely depends upon several acculturation variables, including immigration status (i.e., documented or undocumented), differences in racial classifications, and the amount of time an immigrant has spent in the United States. Undocumented immigrants are less likely to identify themselves as disabled (and in need of public services) because of the reporting requirements that exist at both the federal and state levels. Under California's Proposition 187 and the federal welfare reform law, certain federal and state agencies are required to report any persons suspected of being in the country unlawfully to the Immigration and Naturalization Service.

Another factor that may affect the self-reported rate of disability, particularly within Hispanic populations, is the method of racial classification used by the Census Bureau. Cheryl Utley and Festus Obiakor contend that although the classification scheme developed by the U.S. Census Bureau is the most commonly used method for identifying racial and ethnic groups in the United States, it is also the most problematic.[110] Enwisle and Astone have summarized some of the critical problems associated with the Census Bureau's racial classification scheme. To begin with, "race and ethnicity are confounded when respondents fall under more than one category (i.e., Hispanic, Latino, and Puerto Rican). The amount of information gathered on the ethnicity of a particular group varies among groups (i.e., there is an abundance of information gathered on Pacific Islanders, while little is collected for Haitians)." And finally, "individuals may prefer to be acknowledged by categories different from those offered (i.e., Black rather than African American)."[111] Anita Leal-Idrogo also noted that "almost 90 percent of the Hispanic population is typically categorized as White in racial classifications."[112]

If immigrants from Latin America and Asia are closely aligned with the attitudes and culture of their country of origin, they may not self-identify on a census survey as being disabled because of the negative perceptions and attitudes about disability that exist within these cultures. Ethnicity is often directly related to attitudes about disability. Asians have been found to have the least favorable attitudes about disability of any ethnic minority group.[113] Paul Leung points out that the Chinese character for disability, in fact, implies that a person is "useless or crippled." He says there is a widespread perception within Asian cultures that disability exists because of what one did in a previous life, and it brings about shame to the entire family.[114] This attitude and perception of disability as being a punishment or a shameful experience is documented within several of the testimonies at the 1998 NCD hearing in San Francisco. Throughout the hearing, Hispanic and Asian/Pacific Islander witnesses repeatedly used such words as "shame," "guilt," "inconvenience," and "burden" when referring to their disability or the disability of a family member. These multiple factors (immigration status, differences in racial classification, and cultural attitudes about disability) can have a direct impact on the self-reported rate of disability within Hispanic and Asian/Pacific Islander populations in the United States.

For these reasons, Leung argues that the current national estimates probably do not accurately reflect the reality of the prevalence of disability among Asians and Pacific Islanders.[115] Recent studies on the prevalence of disability among racial and ethnic minorities suggest that there is a direct link between the rate of disability in minority communities and various socioeconomic factors, such as income, poverty, and occupation.[116] Drawing on this data, Leung concludes that some Asian and Pacific Islander ethnic groups "may have a higher rate of disability than the majority population" because of their "higher rates of poverty and representation in service occupations."[117]

This argument can be applied to certain segments of the Hispanic population as well. According to a 1998 report by the U.S. Census Bureau, the poverty rate for Hispanics (27.1 %) is one of the highest in the nation.[118] The level of financial deprivation among Hispanics with disabilities is even greater. A 1996 article by Anna Santiago, Francisco Villarruel, and Michael Leahy reported that three out of four Latinos with disabilities had less than a high school education, and nearly 60 percent had annual earnings less than $4,000.[119] "Relatively few Latinos with disabilities (17 percent of Latina women and 42 percent of Latino men) participate in the labor force," they wrote, "and for those disabled Latinos who do enter the labor force, the chances of being unemployed are high: 22 percent of Latina women and 24 percent of Latino men." The authors argued that the rate of disability among Latinos was probably higher than expected, particularly given the "sustained levels of growth within the Latino population and greater exposure to health and occupation risks." When the national data are disaggregated and a specific study is conducted on the prevalence of disability among ethnic and racial minorities in California, Leung, Santiago, Villarruel, and Leahy appear to be correct. The current national estimates do not seem to accurately reflect the prevalence of disability among Hispanics and Asians/Pacific Islanders in California, and these populations do, in fact, have a higher rate of mobility and self-care limitations than the majority population in the state.

According to a recent U.S. Census Bureau report, 20.6 percent of the general population has some type of disability.[120] In California, with approximately 33 million residents, this means that at least 6 million people deal with disability issues on a day-to-day basis, a conservative estimate at best.[121] When this figure is broken down by race and ethnicity, the prevalence of disability among racial and ethnic minorities in the state appears to mirror the national data. The 1990 federal census of population, social, and economic characteristics of California, issued in

September of 1993, showed that Native Americans had the highest rate of work disability in California (14.74%), followed by African Americans (11.74%) and Whites (7.64%).[122] The rate among Hispanics was 5.75 percent and among Asians/Pacific Islanders, 4.78 percent.[123] Although these figures seem to support the "Hispanic and Asian/Pacific Islander exception," they diverge from the national estimates in a significant respect. Hispanics and Asians/Pacific Islanders in California have a higher rate of mobility and self-care limitations than the majority population. As reflected in the national estimates, Native Americans have the highest rate of mobility limitations in California (3.98%), followed closely by African Americans (3.87%). Unlike the national estimates, however, Asians/Pacific Islanders have the third highest rate of mobility limitations in California (2.42%), followed by Hispanics (2.18%). Whites, in contrast, have the lowest rate of mobility limitations of any racial or ethnic group in the state (1.89%). A similar pattern appears in the prevalence of self-care limitations in California. African Americans have the highest rate (7.10%), followed by Asians/Pacific Islanders (5.94%), Hispanics (5.22%), and Native Americans (4.58%). Whites have the lowest rate of self-care limitations of any racial or ethnic group in the state (2.87%).[124] Based on the cultural variables and figures noted above, there is strong reason to believe that the national estimates do not accurately reflect the rate of disability among Hispanics and Asians/Pacific Islanders.

Unfortunately, because of the widespread publication of these national figures, the service delivery system in California has tended to focus on the needs of Whites, African Americans, and Native Americans with disabilities, and to direct little attention to serving the needs of Hispanics and Asians/Pacific Islanders with disabilities.[125] This oversight appears to have substantially reduced the effectiveness of service delivery for Hispanics and Asians/Pacific Islanders with disabilities in California. According to the 1997 annual performance report for the California state independent living services program, "Data on the ethnicity of persons served by CILs over the past three years indicate that Black/African American individuals are being well served by nearly all centers in comparison to their incidence in the centers service area population." In contrast, only two or three centers serve Hispanic individuals in numbers reflective of their communities, and no center serves persons of Asian heritage in numbers reflective of the general population.[126] This pattern of inequitable service delivery for Hispanics and Asians/Pacific Islanders with disabilities is also documented in the testimonies at the 1998

NCD hearing in San Francisco. In her videotaped testimony, Lourdes Mugas Talan, an independent living specialist at the Hawaii Centers for Independent Living, noted the following:

> Another issue that concerns me is when working with the immigrant population, especially people of my own ethnicity, social services are not really ready to accept them and to be able to provide services.

Of the 69 people who testified at the hearing, almost half (47.8%) were individuals from Asian and Pacific Islander cultures. People of Hispanic origin constituted 17.4 percent of the witnesses, and only 10.1 percent were African American. Whites comprised 20.3 percent of the witnesses, and fewer than 1 percent were Native American.

The fact that more than 65 percent of the respondents at the hearing were Hispanic or Asian/Pacific Islander suggests the sense of isolation and frustration existing within these communities, in part because of the unequal treatment they experience in the service delivery system in California. In honest and eloquent testimony, Ramona Chacon, a parent of a young man with a disability, expressed her feelings:

> At one point my sister told me, "You know, you always seem like you're fighting, because every time you talk, you can't talk without arguing." And then I realized that you have to fight the school district, and sometimes have problems with your landlord, and you have to fight the regional center who is supposed to be helping you....All these systems that are supposed to be helping you...it's very, very hard emotionally and mentally to always constantly fight and always threaten to file a lawsuit....Within each school district they should have some way where parents can go to an IEP meeting for their child with another parent or with an advocate....We need to be able to reach the families because when you have a child with so many different needs, you feel so isolated at times.

### Recommendations

The testimony and evidence reviewed in this chapter indicates that Hispanics and Asians/Pacific Islanders not only experience disability at a higher rate than reported in the national estimates, they also experience inequalities in service delivery as a result of this statistical inaccuracy, which can often lead to feelings of frustration and isolation. The California experience, moreover, raises questions about nationwide demographics of disability in the Hispanic and Asian/Pacific Islander communities. NCD recommends:

- The U.S. Bureau of the Census and the Bureau of Labor Statistics, working with the National Institute on Disability and Rehabilitation Research and the National Center for Health Statistics, should develop alternative methods for tracking the prevalence of disability within racial/ethnic minority communities nationally and at the state, local, and tribal government levels.

In order to obtain a more accurate count of people living in poor minority and immigrant neighborhoods, Representative Dan Miller (R-Fla.), head of the House panel that oversees the census, and Representative Carrie Meeks (D-Fla.) introduced legislation to encourage the hiring of minority individuals as census takers. They said "current research shows that accuracy is increased when members of those communities help in counting."[127] Whether by legislation or other policy means, NCD recommends that the Census Bureau do targeted recruitment of qualified minorities with disabilities as it hires workers for census taking. NCD recommends:

- The Census Bureau should make affirmative action efforts to hire minority and bilingual individuals with disabilities as part of the workforce that will assist with Census 2000.

For a variety of historical reasons, individuals from minority communities may be reluctant to participate in governmental surveys because of a fear of intrusion. When coupled with the negative perceptions of disability that exist within many minority communities, this leads to a decreased willingness on the part of minority individuals with disabilities to participate in census surveys and identify themselves as having a disability.

Given these cultural factors, NCD recommends that the Census Bureau use local minority media and community resources as a means of communicating better the purposes and uses of census data related to disability. All communication should be available in multiple languages, and should be disseminated through nontraditional means, (e.g., placing inserts in utility bills, paychecks, grocery store bags; publishing information on the World Wide Web; posting flyers in areas frequented by minority individuals with disabilities).

In order to address the inequities that exist in service delivery for Hispanics and Asians/Pacific Islanders with disabilities, NCD recommends that federal disability programs conduct a review of their clientele to determine the effectiveness of service delivery for these populations.

Because of the widespread tendency to lump many distinct ethnic groups into a few broad categories (Native Americans, African Americans, Hispanics, and Asians/Pacific Islanders), and to make generalizations based on this categorization, significant cultural differences have been masked, which has had a direct impact on the effectiveness of service delivery for minority individuals with disabilities and their families. NCD recommends:

- NIDRR should fund nationwide studies that will explore the prevalence and experience of disability within different ethnic groups in a particular cultural community.

Research should be supported that studies in-group variability based on quantifiable data, and processes should be in place to control for the confounding of such variables as location (e.g., urban, rural, or suburban), acculturation, language, and socioeconomic level.[128] Researchers and disability service agencies should not assume that the experience of a Mexican individual with a disability will mirror that of a Puerto Rican individual with a disability, or that the experience of an immigrant with a disability will directly coincide with that of a nonimmigrant with a disability.

# IV. CONCLUSION

More than two centuries ago, a promise was made to the American people in the Declaration of Independence—a promise that "all men are created equal" and "are endowed by their Creator with certain unalienable Rights," including the right to "Life, Liberty and the pursuit of Happiness."[129] Less than a century later, in 1863, President Abraham Lincoln reminded America of this promise of freedom and equality in his address at Gettysburg, Pennsylvania, and vowed to fight until that promise was fulfilled for all of the nation's people, regardless of race: "Four score and seven years ago our fathers brought forth on this continent, a new nation, conceived in Liberty, and dedicated to the proposition that all men are created equal."[130] On January 1, 1863, President Lincoln officially renewed this promise by signing the Emancipation Proclamation, and in 1865, it was added to the Bill of Rights when Congress approved the Thirteenth Amendment to the Constitution, which outlawed slavery in the United States.

In spite of this renewed promise, exactly one century later, on August 28, 1963, in his famous address at the Lincoln Memorial, the Reverend Martin Luther King, Jr., reminded America once again of the promise of freedom and equality, and noted that it had yet to be fulfilled for the nation's citizens of color: "Five score years ago, a great American, in whose symbolic shadow we stand, signed the Emancipation Proclamation.... But one hundred years later, we must face the tragic fact that the Negro is still not free."[131]

Spurred on by King's powerful reminder, one year later America once again renewed the promise of freedom and equality with the passage of the Civil Rights Act of 1964. This Act went a long way toward fulfilling the promise of freedom and equality for some segments of the American population. For one segment, however, people with disabilities, the promise had yet to be fulfilled.

Less than 30 years later, on July 26, 1990, President George Bush officially extended the promise of freedom and equality to the nation's citizens with disabilities when he signed into law the Americans with Disabilities Act. At the signing ceremony for the Act, Bush declared:

> Three weeks ago we celebrated our nation's Independence Day. Today, we're here to rejoice in and celebrate another "Independence Day," one that is

> long overdue....Our success with this Act proves that we are keeping faith with the spirit of our courageous forefathers who wrote in the Declaration of Independence: "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights." These words have been our guide for more than two centuries as we've labored to form our more perfect union. But tragically, for too many Americans, the blessings of liberty have been limited or even denied. The Civil Rights Act of '64 took a bold step toward righting that wrong. But the stark fact remained that people with disabilities were still victims of segregation and discrimination, and this was intolerable. Today's legislation brings us closer to that day when no Americans will ever again be deprived of their basic guarantee of life, liberty, and the pursuit of happiness.

After he made this majestic declaration of freedom and equality, Bush turned to the four White activists with disabilities near him and proclaimed, "Let the shameful wall of exclusion finally come tumbling down." Noticeably absent from this picture were any minority individuals with disabilities. For these individuals, the history of unfulfilled promises would remain a continuing legacy. The shameful wall of exclusion was, indeed, still a prevalent reality for America's disabled citizens of color.

In an attempt to tear down this wall of exclusion and fulfill the promise of freedom and equality for all of the nation's citizens with disabilities, the National Council on Disability created an "agenda for the future" in 1992 that identified the unmet needs of minority group members with disabilities as a national policy priority. In spite of this agenda for the future, as the 10th anniversary of ADA approaches, minority individuals with disabilities and their families are hardly closer to realizing the promise of freedom and equality than they were six years ago. The barriers to necessary resources and culturally competent service delivery that existed in 1992 continue to exist today.

In order to "tear down this wall" of exclusion once and for all, people with disabilities and their families from diverse cultural communities came forward at the 1998 NCD hearing in San Francisco to insist that the "agenda for the future" be transformed into an immediate "course of action for today." In his testimony, Vernon Phillips, a freelance writer and musician who is blind, stated that it is time to "make some changes and deal with people's realistic circumstances, and not just what looks and sounds good." "I hope today can be the start," he said, "the start for better things." In answer to this call for action, NCD has charted out a "course of action for today," a declaration of interdependence for minority individuals with disabilities and their families, which if implemented will represent substantial progress toward the promise of freedom and equality for minority individuals with disabilities and their families.

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# Appendix

## MISSION OF THE NATIONAL COUNCIL ON DISABILITY

### Overview and Purpose

NCD is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

### Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 USC 12101 et seq.).
- Advising the President, Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services

within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the Commissioner with respect to the policies and conduct of the Rehabilitation Services Administration.
- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of NCD to promote the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report.*

## International

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

## Consumers Served and Current Activities

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became the Americans with Disabilities Act (ADA). NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

## Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.

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